



# TARC NEWSLETTER

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

## August 2009

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## WHY I LIE AWAKE ON WARM SUMMER NIGHTS UNABLE TO SLEEP

by Executive Director, John F. Gajda

Summer is usually a slow time of year for public policy. The state legislative session is over, Congress usually goes on a long recess and many bureaucrats are literally on vacation. It usually gives me some time to sit back, catch up on my email, read reports, reflect on the first half of the year, and allow the action (or lack of action in some cases) in the first half of the year percolate.

The other night I made the mistake of trying to catch up reading emails right before I retired for the evening and I found myself tossing and turning, unable to sleep. What was bubbling up to the surface that evening were some serious concerns about the future of service for people with disabilities and their families that are resulting in a sleepless summer night. Even counting bills in my head (which usually works better than sheep for me!) didn't help me fall asleep.

So, rather than tossing and turning, I am up at my computer typing so that I can share some of my concerns, which I have gathered from reading the information in my email inbox, with you. They are in no particular order and the list is not all inclusive but tonight this is what is keeping me awake.

### # 1 - The Fiscal Future of Oklahoma State Government

When State Treasurer Scott Meacham unveiled in July that revenue for both the last month of the just completed fiscal year (June 2009) and the fiscal year as a whole were lower than the previous year I couldn't help but wonder where funding is headed?

It's natural to be concerned about what could happen in the just-started state budget for FY '10 that just began on July 1st with this pessimistic news. Meacham was willing to speculate: "It appears very likely at this point that Fiscal Year 2010 revenues will be less than originally estimated by the tax commission. That means a revenue shortfall is probable."

Meacham and others are talking about what to do about it. According to the Tulsa World, "Cutting appropriations to agencies would be the first action. Meacham is asking state agency directors, many of whom are dealing with 7

*"Awake" continued on pg 2*



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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percent cuts this fiscal year, to look for further reductions because of the likelihood of a revenue shortfall. ... If the revenue shortfall is prolonged or steep, budget cuts likely won't be enough, Meacham said. When cuts start affecting employees and vital services, the rainy day fund has to be considered."

The state revenue picture is an ominous cloud over services for people with disabilities in a year when services are at best at a standstill level. Further cuts can only lead to further losses in services. If the situation worsens, advocates need to be willing to urge our state leaders to take steps to maintain adequate and consistent public services for all Oklahomans, particularly those with disabilities.

Here are some things that could be done:

- Call a special session of the Legislature later in the fall. Treasurer Meacham and Governor Brad Henry can only make across-the-board cuts. We elect the Legislature to determine if cuts affect employees and vital services and select the best course. Let's demand that they make strategic, rational cuts—if any cuts are needed—that maintain the programs that people with disabilities need.
- Use the Rainy Day Fund to help fill a shortfall if it does materialize. The Fund was created for this purpose and three-eighths of it may be used ONLY for this purpose
- Get serious about revenue and expenditure forecasting. We should demand the state create and update professional five-year forecasts of revenues, expenditures, and service levels so we can see where we're headed in the long run and make the best decisions for the next few years, not for the next few months.

Oklahoma has tools to deal with this recession without panicking. Our Rainy Day Fund was designed to deal with larger budget gaps and we are fortunate to have sufficient resources to do so. And our Legislature can craft a revised budget that best gets Oklahoma through another round of trying budget times. We could do better, though.

Using the Rainy Day Fund during the recovery would maintain services when they are needed and prepare state agencies and programs to make investments in and during the economic recovery. Long-term forecasting

would help us identify shortfalls sooner, understand their real impacts, and address them strategically rather than haphazardly. Using and improving these tools can help us be sure that Oklahoma adequately invests in services.

*(\*Thanks to The Oklahoma Policy Institute for the suggestions on what could be done about revenue shortfalls. Check out their website at [www.okpolicy.org](http://www.okpolicy.org))*

## **# 2 – Health Care Reform**

We hear a lot in the news about the health care reform debate and although it is not often mentioned, the result is vital for people with intellectual and developmental disabilities.

There is a broad consensus that America's health care system needs reform. Spending is increasing yet, over 46 million Americans are uninsured and we have poorer health outcomes than other industrialized countries.

All stakeholders agree that reform must provide affordable coverage, improve quality and lower costs. To achieve these goals, emphasis has shifted to prevention helping transform our health care system's focus from services provided to performance.

But we must remind those who will be making decisions about these changes that Health Care Reform is important to people with disabilities. Medicaid is the largest program that provides health care and long term services and supports for persons with disabilities. Medicaid has an institutional bias which makes it difficult for persons with disabilities to receive services in community-based settings rather than in large congregate settings. Consequently, over 300,000 people with disabilities are on waiting lists for home and community based long term services and supports across the country. The average wait is 8-10 years.

Our current health care system is principally designed to meet short term or "acute" care needs. There is a tremendous gap in long term care (LTC) for the general population, including people with disabilities who often need assistance with activities of daily living throughout their lifetimes, such as getting dressed, taking medication, preparing meals, and managing money. Only 3% of Americans have private long term care insurance due to its high costs and Medicare provides only very limited LTC coverage. This leaves the overburdened and institutionally

*"Awake" continued on pg 3*

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biased Medicaid program as the primary provider of LTC.

People with disabilities frequently depend on habilitation and rehabilitation services as well as durable medical equipment, prosthetics, orthotics (DMEPOS) to maintain and improve function. These services and products must be included in any new health plans developed as part of health care reform.

According to the 2002 U.S. Surgeon General’s report, “Closing the Gap: A National Blue Print to Improve the Health Care Needs of Persons with Mental Retardation”, people with disabilities experience poorer health and have less access to medical care than the general population. Many factors contribute to this disparity, including difficulty recognizing and communicating health care needs, the shortage of qualified, trained health care professionals who are willing to treat people with disabilities; and inaccessible medical equipment for those with mobility impairments (such as examination tables and weight scales). In addition, low Medicaid provider reimbursement rates have been an ongoing cause of inadequate access to quality health care for individuals with disabilities.

The Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national disability organizations, has developed very specific recommendations regarding the needs of people with disabilities in health care reform:

- Allowing states to offer additional services under the 1915(i) Medicaid Home and Community-Based Services (HCBS) Waivers State Plan Option.
- Increasing the federal share of Medicaid, known as the Federal Medical Assistance Percentage (or FMAP) for HCBS and during periods of economic downturn.
- Strengthening long-term services and supports.
- Prohibiting private health insurance exclusions for pre-existing conditions.
- Restricting the consideration of health status in setting premiums.
- Expanding Medicaid to cover individuals with incomes up to 133 percent of the federal poverty line (approximately \$29,000 per year for a family of four).
- Ensuring that minimum covered benefits include products and services that enable people with disabilities to maintain and improve function, such as rehabilitation and

habilitation services, durable medical equipment (such as wheelchairs and augmentative communication devices) and prosthetics and orthotics.

- Requiring training of physicians, dentists, and allied health professionals on how to treat persons with disabilities.
- Integrating health disparities based on disabilities on the same basis as racial and ethnic disparities in research and program development.
- Ensuring prevention programs include a focus on individuals with disabilities.
- Increasing reimbursement rates for primary care services in Medicaid up to Medicare levels, with 100% federal funding (phased in over several years).

Whether final health care reform legislation includes meaningful improvements in health care for people with disabilities will depend, in part, on the active involvement of individual advocates and disability organizations across the country. There are hundreds, if not thousands, of powerful constituencies that have a great stake in health care reform. It is up to us to make sure our priorities are included.

“The Tulsa City Council attempted to push through an ordinance change that would restrict the ability of people with disabilities to live freely in the community...We can’t let NIMBY be resurrected.”

*(\*Thanks to the The Arc of the U.S. for most of this information)*

### # 3 - NIMBY

For those of you who don’t know, the acronym NIMBY stands for “not in my backyard.” This was a prevailing attitude during the early years of building a system of community services for people with disabilities in Oklahoma. That task is not complete, but I had assumed that this negative, prejudicial attitude was dead.

Apparently not! The NIMBY attitude has reared its head again. In Tulsa, the City Council is trying to push through an ordinance change that would restrict the ability of people with disabilities to live freely in the community wherever they choose. This session the Oklahoma Legislature, in a quick move toward the end of the session that many missed, amended HB 1414 to make it more difficult to establish treatment facilities, transitional living facilities, halfway houses and any facility used for detoxification in the community.

*“Awake” continued on pg. 4*

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The marked decrease in acceptance and tolerance for those who are “different” that motivates these moves is changing the climate in Oklahoma for the development of community based programs. We can’t let NIMBY be resurrected.

#### # 4 - Seniors 1, People With Disabilities 0

When the going gets tough and resources get scarce, the easiest way for decision makers to deal with groups competing for these limited resources is to set the groups up to battle each other. That is exactly what language inserted into HB 1216, the Oklahoma Department of Human Services appropriation bill, by the Oklahoma Legislature this year did. The language states that “It is the intent of the ...Oklahoma Legislature that the Commission for Human Services continue to fund the Advantage Waiver ...with all the state, federal and other existing financial resources available to Commission.”

At a time when the Developmental Disabilities Service Division (DDSD) waiver has a large and growing waiting list and the Advantage Waiver Program in the Aging Services Division has no waiting list, the Legislature has directed OKDHS to prioritize funding for the Advantage Waiver.

In the battle between the elderly and people with disabilities, which has been set up by this legislative direction, the elderly have won one. In the long run though, we all lose when the legislature is unwilling to address all needs and tries to play one group off another.

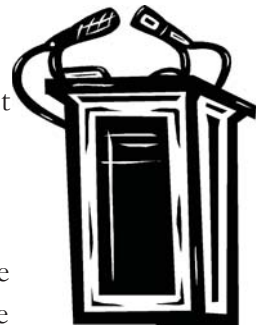
**Conclusion** - If you care about people with disabilities and their families, reading emails that deal with current public policy issues in the evening could be bad for your sleep. There are many serious evolving issues that can impact their lives. These are only a few. I need your help to deal with some of my nightmares!

*The 2009 Advocacy Awards are  
Coming Soon!*

**It is time to start thinking of outstanding advocates to nominate for the 19th annual TARC Advocacy Awards. To learn more visit us online at [www.ddadvocacy.net](http://www.ddadvocacy.net)**

## President Obama Marks 19th Anniversary of the Americans with Disabilities Act (ADA)

On July 24, in a White House ceremony with many people with disabilities and advocates in attendance, President Obama marked the 19th Anniversary of the Americans with Disabilities Act by announcing that the United States will sign the International Convention on the Rights of Persons with Disabilities (CRPD). The President touched on many milestones that the ADA has accomplished, including reasons why it was established initially, “What was needed was a bill of rights for persons with disabilities, and that’s what the ADA was. It was a formal acknowledgment that Americans with disabilities are Americans first, and they are entitled to the same rights and freedoms as everybody else: a right to belong and participate fully in the American experience; a right to dignity and respect in the workplace and beyond; the freedom to make of our lives what we will.” But milestones like this must not only be enforced at home but also be recognized universally and promoted around the world.



This is why on July 30th Susan Rice joined 140 other nations in signing the United Nations Convention on the Rights of Persons with Disabilities. Upon her signature, the U.S. must uphold the general purpose of the treaty, but is not legally bound under international law to any specific article until the Senate ratifies the treaty. Senate ratification requires a 2/3rds majority. The CRPD addresses barriers that impede the full inclusion and participation of people with disabilities in their communities. Its provisions touch on all aspects of daily life, such as education, employment, living independently and being included in community life.

President Obama was introduced by Secretary of State Hillary Rodham Clinton. Nearly a dozen members of Congress who played instrumental roles in the enactments of the ADA also participated. Read the President’s remarks at:

[http://www.whitehouse.gov/the\\_press\\_office/Remarks-by-the-President-on-Rights-of-Persons-with-Disabilities-Proclamation-Signing](http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-on-Rights-of-Persons-with-Disabilities-Proclamation-Signing).

# NIH Issues Research Plan on Fragile X Syndrome and Associated Disorders



The National Institutes of Health has developed a research plan to advance the understanding of fragile X syndrome and its associated conditions, fragile X-associated tremor/ataxia syndrome and fragile X-associated primary ovarian insufficiency. Fragile X syndrome causes intellectual and developmental disabilities and results from a mutation in a gene on the X chromosome.

The plan puts forward goals to guide future research, setting research priorities for each of the conditions. A major priority of the plan is to investigate the biological processes underlying all three disorders and how to better diagnose and treat them. Other priorities are studying how widespread the gene variations are in the population and how the three conditions affect families.

Although the three disorders have very different symptoms, all result from variations in the same gene, known as the Fragile X Mental Retardation 1 (FMR1) gene. Full mutation of the gene means that cells do not produce a protein involved with communications between neurons in the central nervous system. The resulting disorder, Fragile X syndrome (FXS), occurs in approximately one in 2,500 births. People with FXS often have intellectual disabilities ranging from mild to severe. They may also have emotional and behavioral problems, including attention problems, hyperactivity, anxiety, aggression, and autism or autism spectrum disorder.

People with a less dramatic change in the gene have what is called a pre-mutation, which increases their chance of having a child with FXS.

These people may not have any apparent health problems or may have symptoms of Fragile X-associated Tremor/Ataxia syndrome or Fragile X-Associated Primary Ovarian Insufficiency.

Fragile X-associated Tremor/Ataxia syndrome (FXTAS) occurs primarily in older men. The principal symptoms are tremor and gait problems, but the condition also includes cognitive decline, anxiety, and de-

pression. Fragile X-associated Primary Ovarian Insufficiency (FXPOI) occurs in women of childbearing age. Women with FXPOI may experience early infertility and increased risk of osteoporosis and heart disease.

“Collectively, these disorders represent a major health burden and have far-reaching implications for individuals as well as their family members,” said Tiina Urv, Ph.D., of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, chair of the trans-NIH Fragile X Research Coordinating Group. It is possible, Dr. Urv explained, for the gene to be abnormal in multiple family members. For example, the mother of a child with FXS may eventually show symptoms of FXPOI, and her father, and the child’s grandfather, may develop FXTAS. “These disorders may affect multiple family members, and multiple generations,” Dr. Urv said.

To develop the plan, the NIH convened three working groups of experts, one for each of the conditions. Members of each group included experts from the scientific community, members of advocacy groups for individuals and their families affected by the disorders, and other federal agencies. The research plan identifies research goals for each of the three conditions, and outlines strategies for better diagnosis, treatment and prevention of the three disorders.

“The goals were designed to be used by the NIH and FXS, FXTAS, and FXPOI research communities and to be shared with other federal agencies to facilitate coordinated research activities that will lead to timely detection, diagnosis, treatment, and prevention of the targeted disorders,” the report stated.

The report also highlights ongoing research, including collaborative efforts from several NIH institutes: the NICHD, the National Institute of Neurological Disorders and Stroke, the National Institute of General Medical Sciences, the National Institute of Mental Health, and the National Institute on Aging. The NIH funds a network of centers devoted to Fragile X syndrome and its associated conditions, as well as studies by independent scientists.

The release is available at

[http://www.nichd.nih.gov/publications/pubs\\_details.cfm?from=&pubs\\_id=5729](http://www.nichd.nih.gov/publications/pubs_details.cfm?from=&pubs_id=5729).

## Starving the Beast: Government in Lean Times

Most state agencies received basically flat funding or were dealt budget cuts of 5 to 7 percent for the new fiscal year beginning July 1st, even as inflation increased operating expenditures and the cost of employee health care and retirement contributions continue to mount. The result is that most agencies are being underfunded for the basic functions and missions that they are expected to accomplish, whether that is operating schools or parks, regulating environmental quality or nursing homes, protecting at-risk children, or preserving public safety.

But what does this situation mean for the agencies, departments, and school districts that operate public services? We usually don't hear stories about the impact of underfunding unless and until there is a crisis. Yet the reality is that many public agencies at all levels of government, especially regulatory and administrative agencies, are perpetually underfunded. Resources are always scarce, and even in good budgetary times, most legislators prefer to fund programs that provide direct benefits to their constituents than those that do the unglamorous work of licensing, inspecting, investigating, and adjudicating. This is especially true here in Oklahoma, where we are among the bottom five states in the amount we spend per person on state and local government

Recently, the journal Health Affairs published an interview with Kerry Weems, who served as Interim Director of one of those unheralded but vital regulatory agencies, the Centers for Medicare and Medicaid Services (CMS), during the last 18 months of the Bush Administration. CMS is charged with overseeing expenditures of almost \$700 billion annually in the two major public health care programs. In particular, it has the responsibility for preventing and investigating waste, fraud and abuse in these programs. But in Weems' view, one that is shared by many others, CMS is not staffed at levels necessary for it to fulfill its mission. Here's how he describes the impact that a shortage of resources has on his former agency:

And in many ways, right now CMS behaves like a resource-starved agency, which it is. The staff feels a sense of fatalism when they begin complicated tasks that carry out the law. The sense develops because while the agency will do its best, we don't have enough re-

sources to do all of these tasks well, so our final products are not always 100 percent...

CMS is a weakened organization. It has the capacity to pay bills and prepare the annual payment notices. But after that, there is little capacity, much less time, to develop innovative approaches to health care, to think through what a system of higher quality would look like.

There is a widely-held belief that cutting budgets, or keeping funding levels flat over an extended stretch, is healthy for government by forcing it to trim the fat and become leaner and more efficient. In reality, "starving the government beast" has similar effects to starving an individual. Before long, that which is being starved becomes weak, lethargic, and dispirited. As Weems discusses for CMS, underfunded agencies become less efficient because they lack the resources to do their job well. Operating on a shoestring also means being unable to invest the time and resources needed to innovate and think creatively. And in overworked, understaffed agencies, staff suffers from fatigue and declining morale, which tends to lead to rapid turnover among the better employees and a critical loss of experience and expertise.

The Health Affairs article was titled "Doing More With Less". That is what we are demanding of many of our public agencies, nationally and in Oklahoma, especially but not only in a time of declining revenues. We need to be asking whether this is a reasonable expectation, and if not, how we are going to get our expectations of governments back in alignment with the resources we provide them.

More comments and information can be located on the blog at <http://okpolicy.org/blog>.



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Call 1-800-688-TARC or visit  
[www.ddadvocacy.net](http://www.ddadvocacy.net)  
to become a member of TARC.

# Disaboom Launches Disability Organizations Directory

## Directory Provides Valuable Disability Resource for the Community



participants learn to play adaptive sports to those that will make the transition as a college student with disabilities a little easier. This section's 20 sub-categories include assistive technology, ADA, baby boomers, and disabled veterans, among others.

Each entry's listing contains brief information about the organization, its mission and services, and a link to the organization's website. The Disaboom research team will continue to add new organizations on a regular basis.

"We hope that this directory, in addition to our Disability Scholarships Directory, will prove to be highly useful to the Disaboom community and to people with disabilities at large," notes Dority.

Disaboom's Disability Organizations Directory can be found at [www.disaboom.com](http://www.disaboom.com).

## Report: Cost-Effective Olmstead Principles Are Necessary for Healthcare Reform, Civil Rights

The Bazelon Center for Mental Health Law asserts in a report issued today that implementing the principles of the landmark Olmstead Supreme Court decision would have a dramatic impact on health care reform and the economy. The report was released in celebration of the 10th anniversary of Olmstead at a press briefing at the National Press Club.

As a call to action, the report details how federal and state governments can use community-based services and supports for people with mental illnesses to save billions of dollars and improve healthcare outcomes.

The Supreme Court ruled in its 1999 Olmstead decision that under the Americans with Disabilities Act (ADA), public services for people with disabilities must be provided in the most integrated setting possible, giving them the opportunity to live independently in the community and not segregated in institutional settings.

Main points of the report include:

- States must determine how many people with disabilities are served in unnecessarily segregated

Disaboom, Inc., the leading online resource for people with disabilities announced the release of its online Disability Organizations Directory. Disaboom, Inc. was founded as an interactive online community dedicated to constantly improving the way people with disabilities or functional limitations live their lives. This site brings together content and tools, ranging from specialized health information to social networking to daily living resources, in a single interactive site.

Disaboom's new extensive directory identifies over 450 organizations that provide disability services, the bulk of which are nonprofits, government agencies, and education services. The directory ranges from organizations on the local level to the international level.

"All disability organizations, whatever their size and reach, exist for one unifying purpose: To help people with disabilities," states Kim Dority, Vice President of Content and Strategy. "Our goal was to create a comprehensive disability resource for the community where anyone could easily locate the organizations that suit their specific needs."

The organization's directory is divided into three main categories: Major Disability Organizations, Disability-Specific Organizations, and Organizations for Living with Disabilities.

Major Disability Organizations includes the all-encompassing national organizations like the American Association of People with Disabilities (AAPD) and American Association on Health and Disability (AAHD).

The Disability-Specific Organizations section focuses on organizations (within 22 categories) that are geared toward a specific condition or disability, from autism to fibromyalgia to multiple sclerosis.

The final section, Organizations for Living with Disabilities, includes associations that cover all the ins and outs of everyday life, from organizations that help

*Continued from pg. 7*

settings and what community-based services are necessary to support reintegration and recovery. They then must shift funding from institutions to community-based services.

- Implementing Olmstead programs through health care reform would save billions of taxpayer dollars by making essential community services available to people with mental illnesses.
- Often pressured by profit-making providers, states continue to waste valuable resources by placing people with mental illnesses in costly, ineffective institutional settings. The cost of a supportive apartment is one eighth that of state hospital care, just over a third of the cost in a board-and-care facility.
- It is critical to promote Supreme Court and other judicial nominees who have an understanding of and intention to uphold Olmstead, the ADA and other civil rights laws.

“On this pivotal anniversary of Olmstead, we must take a hard look at what really needs to be accomplished to adequately serve millions of people with mental illnesses so that they receive the most integrated care possible. We are encouraged by President Obama’s statement of commitment to Olmstead’s civil rights and community integration mandates, and we hope that the release of this report spurs additional action,” said Robert Bernstein, Ph. D, executive director of the Bazelon Center for Mental Health Law.

Presenters at the press briefing spoke to the success of Olmstead programs, such as supportive housing, illness self-management and recovery, case management and crisis residential services. Lois Curtis, a plaintiff in the original Olmstead case, and Irene Kaplan, a witness in the current DAI v. Paterson case challenging “adult homes” in New York, each told moving tales of integrating into the community after spending years in institutional settings.

Ira Burnim, legal director at the Bazelon Center, spoke about Olmstead litigation during the past decade and what the federal government and states can do to implement the historic decision. Robert Bernstein, executive director of the Bazelon Center, highlighted the 10th Anniversary call to action, detailing specific steps that Congress, federal agencies and the states should

take to create community-based care models. He also described how Olmstead programs can guide healthcare reform and save billions of taxpayer dollars.

“We have only seen progress toward implementing Olmstead principles in the past decade through litigation. It is time for states to follow the integration mandate given by the ADA and reinforced by the Supreme Court. They must work to ensure that robust mental health services and supports are available for people with psychiatric disabilities who wish to return to a normal role in their communities after being segregated in institutions,” said Ira Burnim, legal director of the Bazelon Center for Mental Health Law. To view a copy of the report, visit: [http://www.bazelon.org/pdf/Olmstead\\_Call-to-Action.pdf](http://www.bazelon.org/pdf/Olmstead_Call-to-Action.pdf).

## **Education/ Seclusion and Restraint**

Department of Education Secretary Arne Duncan sent a letter to chief state school officers on July 31 urging them to develop, review, and/or revise (if appropriate) as well as publicize their state policies and guidelines to ensure students are protected from unnecessary and inappropriate use of seclusion and restraint. Secretary Duncan highlighted his home state of Illinois’ use of Positive Behavior Intervention and Supports (PBIS) and regulations which limit the use of seclusion and restraint in most circumstances. He also noted that school districts can use one-time funding from the American Recovery and Reinvestment Act (ARRA) to implement school wide PBIS.

Source: Monday Morning Memo

## **Public Input on Emerging Disability Issues**

The National Council on Disability (NCD) is gathering public input for a study of emerging issues and trends affecting the lives of people with disabilities. Information gathered will be used in the development of NCD’s next annual progress report to the President and Congress, entitled National Disability Policy: A Progress Report, which is required by Section 401(b) of the Rehabilitation Act of 1973. The deadline for input is September 15, 2009. For more information see: <http://www.ncd.gov/newsroom/publications/2009/NationalCouncilonDisability.doc>

Source: Monday Morning Memo



## Mayo Clinic Study Questions Belief that Children with Autism Have More Gut Problems

A new study casts doubt on a commonly held but controversial belief that autistic children have more gut problems than their peers.

The Mayo Clinic study, published July 27, 2009 in the *Journal Pediatrics*, found autistic kids in the study were more likely than their nonautistic counterparts to be picky eaters or constipated. But the researchers did not find a significant difference between the two groups when it came to diarrhea, abdominal discomfort, bloating, reflux or vomiting.

“We did not find a difference in gastrointestinal symptoms in total,” said Dr. Samar Ibrahim, lead study author and a Mayo Clinic pediatric gastroenterology fellow.

For years, parents, physicians and researchers have wondered whether people with autism suffered from more digestive problems than the rest of the population. Many children with autism are following aggressive medical regimens aimed at treating suspected gut trouble, including multiple nutritional supplements, anti-fungal medication and perhaps an anti-viral or antibiotic drug. Many also are on a restrictive diet. However, “such treatments should not be provided indiscriminately to children with autism unless there is explicit evidence indicating the presence of a gastrointestinal disorder in a specific case,” the study authors wrote.

The study subjects were 121 children with autism and 242 other children. All were residents of Olmsted County, Minn., home to the Mayo Clinic. Comparing the cumulative incidence of gastrointestinal problems from birth until the late teens showed that the only significant differences were in constipation and feeding issues.

Dr. Mark Gilger, chief of pediatric gastroenterology at Texas Children’s Hospital in Houston, said he did not think the study settled the fiercely debated question. “This is where you say further research is needed because that’s the honest truth,” said Gilger, who wrote a commentary accompanying the study.

It’s possible that subgroups of autistic children might have specific gastrointestinal issues that would not be picked up in a general-population study, said Dr. Geri Dawson, chief science officer for the nonprofit organization Autism Speaks. “There is more work to be done,” she said.

An abstract of the article, “Incident of Gastrointestinal Symptoms in Children with Autism: A Population Based Study” can be read online at <http://pediatrics.aapublications.org/current.dtl>.

Sooner Success is holding a Free Training

### **“Raising a Child with Autism: The Practical Wit & Wisdom of Parents”**

Tuesday, September 29, 2009

Chisholm Trail Technology Center, Seminar Room

Hwy. 33, between Kingfisher and Watonga

Registration: 8:30 a.m.—9:00 a.m.

Workshop: 9:00 a.m.—2:30 p.m.

Lunch On Site: Provided by The Health Occupations Students of America, benefiting Autism Speaks.

Cost \$7.00.

REGISTER EARLY! SEATING IS LIMITED.

Please respond to the Sooner SUCCESS Coordinator in your county by September 22



# TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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## RETURN SERVICE REQUESTED

The TARC newsletter is published monthly by the Tulsa Advocates for the Rights of Citizens With Developmental Disabilities, Inc., to inform readers about issues and legislative action that affect adults and children with developmental disabilities, their families, and professionals working in the field of developmental disabilities. The contents do not necessarily represent the official position of TARC.

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# HELP TARC HELP FAMILIES-BECOME A MEMBER TODAY!

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,  
August 19th  
6:30-7:45 p.m.

Brookside Library, 1207 E. 45th Pl.

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

**iJUNTOS!**  
Support Group for Hispanic Families

Next Meeting: Monday, August 31st  
7:00 to 8:30 p.m.  
St. Thomas Moore Catholic Church,  
2720 S. 129th E. Ave., Tulsa

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.

Next Meeting:  
August 12th  
6:30 p.m.

A representative from DDSD will be joining us this month to talk about the new self-directed services program and answer any questions you may have.

Contact Amie Farinella, 918-582-8272  
For more information

**Connections Asperger's Group**

Next Meeting:  
Wednesday, August 26th 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

Next Meeting:  
Thursday,  
August 27th  
7:00-9:00 p.m.

Kirk of the Hills Presbyterian Church  
4102 E. 61st St., Room B-8

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

**1<sup>ST</sup> TULSA PEOPLE FIRST**  
Tulsa People First

Next Meeting:  
Spaghetti Warehouse  
221 East Brady

August 11th  
Dinner 5:30  
Meeting 6:30

For more information please contact Amie Farinella  
918-582-8272