



TARC NEWSLETTER

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

February 2007

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Debate Over Controversial Treatment of Young Girl Wide-Ranging

by John F. Gajda, TARC Executive Director

The treatment performed on a severely brain-damaged girl whose growth was deliberately stunted to make it easier for her parents to care for her at home has resulted in many objections from disability advocacy groups.

The girl, identified only as Ashley, had surgery in 2004 to remove her uterus and breast tissue at a Seattle hospital and received growth-stunting hormones. She is now 4-foot-5, about a foot shorter than the adult height she probably would have reached, her parents say.

Ashley suffered brain damage from an undetermined cause that was diagnosed shortly after birth. She cannot sit up, walk or speak. Her parents say keeping their little "pillow angel" small will allow them to continue caring for her at home even when she is an adult. Her treatment will also allow her to avoid menstruation and related discomfort, as well as breast cancer, which runs in the family, her parents say.

The details of the treatment came to light when the girl's doctors at Children's Hospital and Regional Medical Center in Seattle described the case in October's *Archives of Pediatrics & Adolescent Medicine*.

Many individuals and groups have taken a stand about this procedure, now referred to as "The Ashley Treatment." Key portions of three position statements are reprinted below.

The original article can be accessed by going to the web site of the journal at <http://www.archpediatrics.com> and going to the October edition in the "Past Issues" section of the web site. The article is titled "**Attenuating Growth in Children With Profound Developmental Disability: A New Approach to an Old Dilemma.**"

Ashley's parents have established a web blog on which comments are being posted. It can be accessed at <http://ashleytreatment.spaces.live.com>.

The treatment of Ashley has generated a wide-ranging debate that is not just about Ashley. It touches our core values and beliefs about people with disabilities.

please see "The Ashley Treatment" on page 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:

16 East 16th Street, Suite 405, Tulsa, Oklahoma 74119-4447

www.ddadvocacy.net tarc@ddadvocacy.net 918-582-8272/800-688-8272 918-582-3628(Fax)

“The Ashley Treatment”, from pg. 1

UCP & The Arc Joint Statement

“The decision by the parents of a young girl with disabilities to medically restrict her physical growth and maturation, now known as “The Ashley Treatment,” has sparked renewed debate of the rights of people with intellectual and developmental disabilities.

We believe that loving parents who are caregivers are not granted special dispensation to sanction irreparable and irreversible surgeries to alter their son or daughter’s physical being primarily for their own convenience or comfort. In this case, the decision drastically altered Ashley’s life. The ethics panel that approved the decision to perform these medical procedures on Ashley provided insufficient counsel to the family and the doctors, since they failed to account for Ashley’s fundamental rights as a person with intellectual and developmental disabilities. In published accounts of the ethics review, consideration of Ashley and her stake in her own civil and human rights was absent.

For decades we have worked to ensure that people with intellectual and developmental disabilities have the same civil and human rights that others enjoy, and that they have the same respect and dignity that all persons receive. Too often, people with intellectual and developmental disabilities are treated as perpetual children. As advocates, we are acutely aware of the profound difficulties parents of sons and daughters with disabilities face, and we know that most of us need support and information so that we may provide the best possible care and nurturance to our children as they grow and become adults.

We remain committed to working together to ensure that all-encompassing and infantilizing interventions such as this are not promoted by our public policies. We work to ensure that communities are aware of the needs of all children and adults who live with significant disabilities, and of the concerns of their families. By learning to include, respect, and value people with the most significant disabilities, we can improve all of our communities.”

Inclusion International Statement

“Inclusion International and its more than 500,000 individual members around the world

expressed its condemnation of the “Ashley Treatment.”

Diane Richler, President of Inclusion International decried the treatment as threefold discrimination against Ashley as a person with a disability, a girl and a child. “Just last month we celebrated the adoption of the new United Nations Convention on the Rights of Persons with a Disability,” said Richler. “Ashley’s situation teaches us that our celebrations were premature. Until the Convention is fully ratified and implemented, discrimination against Ashley and millions in similar situations will continue.” The Convention specifically recognizes the need for special caution in protecting the rights of women and children, for awareness-raising “including at the family level...and foster(ing) respect for the rights of persons with a disability,” for combating stereotypes, for equal treatment under the law, including supports for decision-making, freedom from degrading treatment and the right to ‘full physical development’.

Parents should not be forced into making such hideous choices. Especially in a country with the wealth and resources of the United States, supports should be available so that Ashley could be supported to remain with her family and to grow and develop to her maximum. “It is when our countries and communities let families down, and leave them the full responsibility of care that families are sometimes pushed to make choices that would be unthinkable if their personal and financial resources were not being stretched to the breaking point,” concluded Richler.”

Statement from the Board of Directors of the American Association on Intellectual and Developmental Disabilities

“As leaders of the American Association on Intellectual and Developmental Disabilities, the oldest multidisciplinary association in the United States representing professionals within the field of intellectual and developmental disabilities, we have great sensitivity to the concerns facing parents of children with profoundly disabling conditions. They indeed face many extraordinary challenges as they strive to raise their children, and they should be provided with the supports and services they need to ensure that their children, as any others, have

please see “The Ashley Treatment” on page 3

“The Ashley Treatment”, from pg. 2

opportunities to achieve all that life has to offer. Naturally, these services and supports include medical and habilitation therapies. We as a society should be supportive of innovative approaches to treatment, but we should also demand a thorough evaluation of potential benefits and balance these against carefully considered risks.

As individuals and as an organization, we endorse policies and actions that help families to rear their children with intellectual and other developmental disabilities at home, nurturing their capabilities as well as coping with their impairments. We applaud the efforts of the many caring professionals who are engaged in providing extraordinary care to children with intensive and pervasive support needs and who continue to meet those needs throughout their adult lives.

We also recognize the many challenges faced by physicians as they weigh with families the benefits versus costs of various treatment options and struggle with the complex ethical concerns that can arise. As the current leadership of the former American Association on Mental Retardation and now the American Association on Intellectual and Developmental Disabilities, we view growth-attenuation as a totally unacceptable option.

(Some argue that) growth attenuation offers reasonable expectation of improved quality of life in this case. However, the history of the medical establishment's involvement in exactly these types of quality of life issues has led to the support of some very regrettable past policies (e.g., involuntary sterilization and lifelong involuntary institutionalization).

Thus, this artificial manipulation may have many unforeseen consequences, and while optimism has its place, there is ample reason to suspect that some of these consequences will be deleterious.

Because there was no urgency in this case, a very substantial burden of proof of benefit should have been imposed before moving forward. We see no such evidence of benefit, and despite description of a committee review process (apparently for future cases), there was no mention of including an independent legal advocate for the child or any other professional with explicit expertise in disability rights and autonomy, nor was it apparent that anyone

participating in the process would be knowledgeable about the ever expanding options for in-home supports and services. The lives of parents of children with severe disabilities are profoundly affected, and these individuals are asked to shoulder exceptional responsibilities for care-giving. They should be supported as they strive to meet the extraordinary needs of their children, and we as a society must acknowledge and value their efforts. However, growth attenuation of their children should not be included as an option. Under our law, parents are vested with the responsibility for making health care decisions for their minor children, but parental prerogatives are not absolute. Children have their own distinct rights and protections afforded them as individuals established in ethical principles and legal statutes. These rights should be of central relevance in the current situation, yet they did not seem to receive the attention they deserved.

With a damning combination of uncertain benefits and unknown risks, growth attenuation ... is bad medicine, but this practice has even more troubling implications. By extension, if weight ever becomes a difficulty due to age-associated loss of strength for the parents (rather than obesity of the child), then the rationale would suggest that bariatric surgery or severe restriction in caloric intake would be a form of therapy. If that proves insufficient, the goal of reducing the size of the child could be addressed by “amputation-therapy,” justified by the fact that the patient would never be ambulatory in any event.

It seems painfully obvious that medical practice for an individual can rapidly degenerate if the anxieties of the parents regarding as yet unclear future issues replace the medical best interest of the child as the primary focus, even with the noblest of intentions of all parties involved. We see an enormous potential for abuse here, and given the well-documented history of mistreatment, neglect and devaluation of this population, we are stunned and outraged by the very fact that the relative merits of growth attenuation could, in 2006, be a topic for serious debate in this forum.

While references to slippery slopes should be made with great care, we believe that this practice, if judged acceptable, will open a doorway leading to great tragedy. This door is better left closed.”

Oklahoma APSE Employment Conference Set for March



The 20th Annual Oklahoma APSE Employment Conference will be held March 27-28 at the Oklahoma City Clarion Convention Center. Conference registration is free for attendees who pre-register by March 15.

The 2007 conference is titled “*Work: Discover the Possibilities?*” and will feature keynote speaker David Harp. Harp is an internationally acclaimed cognitive scientist, author and motivational speaker. Harp will show conference attendees how they can be more effective in their work and daily lives.

The conference will include numerous breakout sessions, featuring nationally renowned experts in employment technology and related services. Oklahoma professionals will offer their experience, knowledge and success in providing customized employment for job seekers.

Conference sponsors include the Donna Nigh Foundation, the Zarrow Foundation, DDS and the University of Oklahoma, National Center for Disability Education and Training.

To receive a registration form, contact Judi Goldston at 405-325-0448 or jgoldston@ou.edu.

State Approaches to Serving Students with Autism Spectrum Disorders

Project Forum has released an in-brief policy analysis, clarifying terminology and reporting findings gathered from a survey of state special education staff.

Findings were reported in the following areas: state-level staff time and responsibilities; specific services for Part C eligible children; specific services for students with Asperger Syndrome; types of professional development activities offered; taskforce roles; how states measure outcomes; barriers to providing services to this population; and more.

The most mentioned barrier to serving this growing population was the lack of educational professionals with ASD expertise. To view the analysis, visit: <http://www.projectforum.org/docs/StateApproachestoServingStudentswithAutismSpectrumDisorders.pdf>.

Source: Project Forum

OSDE to Hold IDEA Public Comment Meetings



The Oklahoma State Department of Education (OSDE), Special Education Services Division will hold IDEA 2004 Public Comment Meetings in Oklahoma City and Tulsa in April. Dates, times and locations are listed below:

Tulsa

Friday, April 20, 2007

6:30 p.m.-9:30 p.m.

Tulsa Technology Center, *Riverside Campus*
801 E. 91st St.

Oklahoma City

Monday, April 23, 2007

6:30 p.m.-9:30 p.m.

Metro Technology Center, *Main Bldg., Big Dipper Room*
1600 Springlake Dr.

For more information, contact OSDE at 405-521-4862.

Source: OU Health Sciences Center



TARC

Visit us on the web at:
www.ddadvocacy.net

Reflections on the New Individuals with Disabilities Education Improvement Act



In a recently published law review article, Mark C. Weber discusses how the reauthorized Individuals with Disabilities Education Improvement Act (IDEA) has made special education much more closely aligned with the No Child Left Behind Act.

The article discusses both the improvements of the reauthorized IDEA and the areas where further statutory clarification would be helpful to understand how the two Acts work together. Weber concludes that, “It is the vision of special education as something not all that special which we should be driving reform.” The full article and abstract are available at <http://ssrn.com/abstract=907134>.

Source: Florida Law Review, Vol. 58, p. 7

The Face of the Oklahoma Legislature Changes

When the first session of the 51st Oklahoma Legislature officially convenes on February 5 it will look much different than the old Legislature that adjourned last May.

The Republicans continue to hold a majority in the Oklahoma House but the balance in the Senate has shifted with a near dead heat between Republicans and Democrats. There is a 50/50 split of members between the parties. Only the new Democratic Lieutenant Governor Jerri Askins, who presides over the Senate, gives the Democrats a slight edge.

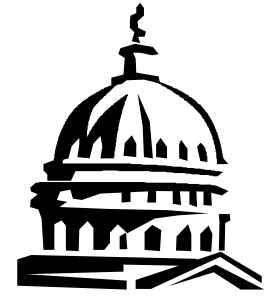
There is a new Republican speaker in the House, Lance Cargill of Harrah, who will put his own leadership stamp on the chamber. Leadership positions in the Senate are being split, with a Democratic President Pro-Tempore and a Republican Co-President, in an interesting power sharing agreement between parties.

Due to term limits and retirements both chambers will see a largest number of new young members and fewer with long-term experience. Only 13 of the 101 House members have served in the legislature for more than six years. None have served more than 10 years. Only eleven of the 48 Senate members have been in the legislature more than six years.

Nine members of the House are not yet 30 years of age with the youngest only 24. The average House member is about 47.4 years old. In the Senate the Average age is about 47.9 years although the youngest is 30.

The large number of young, inexperienced members creates a challenge for advocates for people with disabilities who now have a better perspective on the history of services and funding than many members of the legislature.

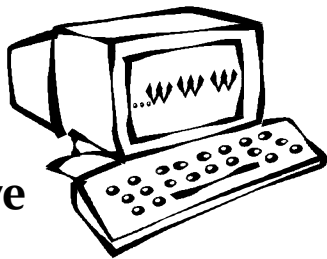
Overall, the number of bills filed in the legislature has decreased this year. Only 1,195 bills, 45 joint resolutions and 11 concurrent resolutions have been filed in the House compared to 1,654 bills and joint resolutions filed last year. In the Senate the number was up slightly with 1,091 bills and 30 joint resolutions being filed. In 2006 the Senate filed 1,034 bills along with 32 joint resolutions. A detailed analysis of those impacting people with disabilities will be included in the March edition of the TARC Newsletter.



Key Deadlines for Second Session of the 2007 Oklahoma Legislature

| Action | House | Senate |
|--|-------------|-------------|
| Session Begins | February 5 | February 5 |
| Deadline for reporting bills from subcommittees | February 22 | --- |
| Deadline for reporting from committees of originating house | March 8 | February 22 |
| Deadline for approval of bill in house of origin | March 15 | March 15 |
| Deadline for reporting from subcommittees in opposite house | April 5 | --- |
| Deadline for reporting bills from committees in opposite house | April 19 | April 5 |
| Deadline for approval of bill in opposite house | April 26 | April 26 |
| Sine Die by 5 p.m. | May 25 | May 25 |

Alliance for Oklahoma's Future Releases Online Legislative Resource



The Alliance for Oklahoma's Future has released its 2007 Legislative and Budget Primer, a new online guide for the upcoming Oklahoma legislative session. It is available at www.okbudgetalliance.org

"The primer is an invaluable resource intended to help Oklahoma citizens better understand how their state legislative system really works," stated Alliance for Oklahoma's Future Chair David Blatt. "Whether you are a complete novice to the legislative process, a six-term legislator, or anyone in between, the 2007 Legislative and Budget Primer will provide you the information you need to be better informed and better engaged on the issues you care about."

Information available in the primer includes:

- a comprehensive listing of the leadership, including committee and subcommittee chairs, in both the State House and Senate;
- an explanation of how the State Senate will function with a historic 24-24 political party tie through a Power-Sharing Agreement;
- a step-by-step explanation of all the stages in the legislative process;
- the basics of the budget process that determine how much money is available to be spent by the Legislature each year; and
- a preview of major funding commitments state legislative leaders will be facing this session.

The 2007 Legislative and Budget Primer can be easily downloaded as a PDF or viewed directly online as a PowerPoint from the Alliance web site www.okbudgetalliance.org. The Alliance is also making hard copies of the primer available upon request; call 405-615-2880 for more information.

Source: Alliance for Oklahoma's Future

IRS Issues Clarification on IRA Charitable Rollovers

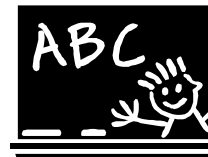


The Internal Revenue Service has released new guidance on the IRA Charitable Rollover, enacted late last year as part of the Pension Protection Act, including helpful Frequently Asked Questions and Answers (FAQs).

The IRS guidance clarifies that checks may be delivered to a charity by the IRA holder, as long as they are made payable to an eligible charity. In addition, the guidance specifies that the \$100,000 distribution limit applies separately to spouses, as long as each holds an IRA and is at least age 70½ (to permit contributions of up to \$200,000 by married couples). For more information, visit www.irs.gov.

Source: IRS

U.S. Department of Education Releases Tool Kit for Parents of Students With Disabilities



The U.S. Department of Education has released a CD version of the tool kit, *Teaching and Assessing Students With Disabilities: Parents' Materials*, designed to assist parents in their efforts to raise the achievement of students with disabilities.

The Parent Tool Kit offers a collection of resources on assessment, instructional practices, behavior and accommodations. These new documents were written specifically for parents and include information they need as they work with schools to ensure that their children are receiving a quality education.

Materials included in the new Parent Tool Kit provide information that will help them become active and informed participants in IEP discussions and other decision-making meetings that support students with disabilities and their families.

To view the materials included in the tool kit, visit www.osepideasthatwork.org/index.asp.

Source: USDE

President's Budget Reveals Broken Promises and Wrong Priorities

Statement of the Consortium for Citizens with Disabilities on the President's FY08 Budget Proposal

At the 16th Anniversary of the Signing of the Americans with Disabilities Act last July, President Bush stated his "commitment to ensuring that the fundamental promises of our democracy are accessible to all our citizens."

The Administration's fiscal year 2008 budget breaks this promise of full citizenship. President Bush's budget and tax policy, emphasizing wealth over opportunity, simply fails to match his rhetoric. Among the key disability related federal programs targeted for elimination, cutbacks, or freezes in funding include:

Broken Promise: Medicaid and Medicare

During the President's State of the Union Address, he stated that "When it comes to health care, government has an obligation to care for the elderly, the disabled and poor children." However, the President's budget includes legislative proposals that would cut key entitlement programs by \$101.5 billion over the next five years — \$75.8 billion in Medicare and \$25.7 billion in Medicaid. Some of these cuts, \$10.2 billion in Medicare and \$12.7 billion in Medicaid, would be achieved through administrative actions by the Centers for Medicare and Medicaid Services (CMS) while the remaining cuts would need to be enacted by Congress.

Broken Promise: Children's Health

Although nearly six million low-income children remain uninsured today, the budget fails to provide sufficient funds for the State Children's Health Insurance Program simply to maintain current levels of coverage and represents a step backward from the goal of covering all low-income children. In addition, small health prevention programs that provide a big impact such as the traumatic brain injury and children's newborn hearing screening program are zeroed out.

Broken Promise: Human Services

During the signing of the Combating Autism Act, President Bush stated that "for the millions of Americans whose lives are affected by autism, today is a day of hope. The Combating Autism Act of 2006 will increase public awareness about this disorder and provide enhanced federal support for autism research and treatment. By creating a national education program for doctors and the public about autism, this legislation will help more people recognize the symptoms of autism. This will lead to early identification and intervention, which is critical for children with autism." However, the President's budget provides no funding for this new law.

Broken Promise: Employment

After promising to expand employment opportunities for people with disabilities as part of his New Freedom Initiative, the President proposed for the seventh year in a row to eliminate the supported employment program that

successfully assists people with significant disabilities to work in the community and be productive tax-paying citizens. For the first time since the Congress added a mandatory increase to the Vocational Rehabilitation State Grant program based on the Consumer Price Index more than two decades ago, this Administration even failed to add the CPI increase to its budget request. Total VR Act funding is cut by \$54 million while millions of Americans with disabilities remain unemployed. In addition, the President again proposes to cut the Assistive Technology program that assists individuals with disabilities to be successful and included in classrooms and at work by over \$4 million.

Broken Promise: Education

The President seeks to level fund the Individuals with Disabilities Education Act (IDEA) State Grant, the Preschool Grant and the Part C Early Intervention programs and cut the IDEA National Activities programs by \$64 million. The IDEA State Grant request would actually decrease the per pupil federal share of funding for students with disabilities below 17%, well below the authorized amount of 40%. That share has dropped about 3% in the last several years. The special education teacher preparation program is frozen at a critical time when school systems grow desperate to hire highly qualified teachers to implement the requirements of No Child Left Behind. A large proportion of special education students are taught every day by unqualified teachers, let alone those who are highly qualified.

Broken Promise: Housing

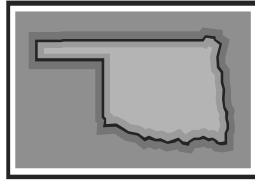
The President's budget proposes to slash the Section 811 Supportive Housing Program for Persons with Disabilities, a 46% cut. Most of the \$113 million cut would come from the program's capital advance component - the only federal program that produces affordable and accessible housing for low-income persons with significant disabilities.

Broken Promise: Research

For the National Institutes of Health, the Administration proposes \$28.6 billion for FY 2008, which is \$310 million less than the funding level in the final FY 2007 Joint Funding resolution passed by the House last week. In addition, the Administration proposes to increase the Global AIDS Transfer out of NIH by \$201 million, effectively cutting the agency's budget by \$511 million in FY 2008 and reducing it to its FY 2005 funding level.

The Consortium for Citizens with Disabilities (CCD) urges the U.S. Congress to reject the Administration's budget cuts and to reaffirm the promise of full citizenship for America's citizens with disabilities.

Oklahoma Receives Grant for Long-Term Care



On January 11, the Centers for Medicaid Services announced that 17 states will receive more than \$23 million in grants for FY 2007 and up to \$900 million over 5 years for demonstration programs that will help build Medicaid long-term care programs to move people to the community and out of institutions. These are the first grants in the “Money Follows the Person” (MFP) “rebalancing” initiative, included in the Deficit Reduction Act of 2005 (DRA), that will eventually total \$1.75 billion over five years (2007-2011). These 17 states expect to move a total of 23,604 people from institutional settings to community-based services.

The first states to receive that funding and the amounts approved for Fiscal Year 2007 are: Wisconsin-\$8,020,388; New York-\$192,981; Washington-\$108,500; Connecticut-\$1,313,823; Michigan-\$2,034,732; Oklahoma-\$3,526,428; Arkansas-\$139,519; Maryland-\$1,000,000; Nebraska-\$202,500; New Hampshire-\$297,671; California-\$90,000; Indiana-\$860,514; Texas: \$143, 401; South Carolina-\$34, 789; Missouri-\$3,398,225; Iowa-\$307,933; Ohio-\$2,079,488.

Through MFP grants, the selected states will receive an enhanced federal match for one year for the community-based services provided to individuals who move from an institution to the community. The states are then obligated to continue to serve the individual in the community within its normal Medicaid matching rate. The enhanced match equals half of the difference between the state’s current match rate and 100 percent. For example, a state which currently receives a 60 percent federal match would receive an 80 percent federal match under MFP [60% + 20%(1/2 of 40%)]. No state may receive more than 90 percent.

The Oklahoma grant will go to the Health Care Authority, the administrative agency for Medicaid, which will be responsible for implementing it.

CMS has indicated that an executive summary of the states’ proposals will be made available on its website in the near future. CMS has indicated that most states plan to begin transitions in the second

year of the demonstration program. A chart showing the amounts awarded to each of the first 17 states and a breakdown of the number of persons to be served can be found at: [http://www.cms.hhs.gov/DeficitReductionAct/Downloads/States1st%20Tierweb\(2\).pdf](http://www.cms.hhs.gov/DeficitReductionAct/Downloads/States1st%20Tierweb(2).pdf).

Source: CMS

Researchers to Create Autism Databank



Scientists at the University of Michigan and 10 other universities will use an initial \$10 million gift from a New York based charitable organization to create a databank of DNA samples from 3,000 autism patients that they hope will identify different kinds of autism and develop treatments.

The gene data could help identify types of autism and treat newborns, similar to the way phenylketonuria, or PKU, a genetic disorder that can cause mental retardation, is detected and treated today.

Source: cbsnews.com

Genes Linked to CdLS Identified



An international team of researchers identified two genes that contribute to Cornelia deLange syndrome (CdLS), a multisystem genetic disease that affects an estimated one in 10,000 children.

In the current study, mutations in two genes of interest cause mental retardation, but with less pronounced facial features and none of the limb defects, such as missing hands or fingers, that are hallmarks of classical cases of CdLS. The genes play important roles in early development, and when mutated, cause brain abnormalities.

This discovery will improve the diagnosis of Cornelia deLange syndrome and also opens an avenue for investigating genetic mechanisms in broader populations of patients with abnormal brain development, including mental retardation and autism.

Source: Children’s Hospital of Philadelphia

Autism News Roundup

Release of New Draft Evidence-Based Guideline About Autism Spectrum Disorder

In a ground-breaking first for New Zealand, health, disability and education professionals and social service agencies will now be able to refer to an evidence-based guideline when diagnosing and supporting people with autism spectrum disorder (ASD).

Lester Mundell, the Ministry of Health's Chief Advisor of Disability Services, says "Autism Spectrum Disorder is a life-long developmental disability, which can affect communication, social interaction and behavior. Its form and severity can vary from person to person, and a range of developmental disorders including Asperger Syndrome, is now considered to be part of the autistic spectrum."

"ASD is a complex group of disorders and there have been conflicting claims about the benefits of certain interventions. To date, international guidelines have covered particular groups, for example children, or a particular series of interventions, for example education or medical approaches. The New Zealand Guideline takes a whole of life and a whole of government perspective."

The draft ASD Guideline is intended to provide guidance on ASD in both children and adults in New Zealand. The guideline will provide people with ASD and those around them up-to-date and reliable evidence for designing and monitoring services and support. It covers identification, diagnosis, ongoing assessment, interventions and services for people with ASD from infancy to adulthood.

Ministry of Education, Team Leader Research in Professional Practice, Joanna Curzon says, "This guideline is in response to many requests from the health and disability sector, people with ASD and their family members for guidance about interventions that work."

Curzon says a review by the Government highlighted gaps in services for people with ASD

and made a number of recommendations to improve the quality of services for people with ASD. In response, the Ministries of Health, Education and the Department of Child, Youth and Family formed a cross-government group to tackle the challenges raised by the review.

"It was this group that responded to the requests from people with ASD and their supporters and agreed that an evidence-based guideline was needed. An ASD Guideline Steering Group has helped to guide the development of the ASD Guideline and the Ministries of Health and Education have jointly sponsored and funded the work."

Lester Mundell says there is now a three-month consultation phase to allow the public - service providers from the disability and education

sectors, parents and caregivers - to review the draft Guideline, provide feedback on how useful they find the Guideline and supply any evidence that may have been overlooked.

"We welcome the public discussion and feedback on this, and we're confident that this will help ensure that the final ASD Guideline is accurate, relevant and useful to everyone who supports people with ASD."

At the same time as the public consultation is taking place, international experts in ASD are peer-reviewing the draft ASD Guideline and an impact analysis is being conducted, commissioned by the Ministries of Health and Education. The results from all three activities will feed into an implementation plan.

The government is determined that the ASD Guideline will lead to improved life outcomes for people with ASD and those around them.

The draft ASD Guideline is on the Ministry of Health's website - www.moh.govt.nz/autismspectrumdisorder.

Source: New Zealand Ministry of Health

"The guideline will provide people with ASD and those around them up-to-date and reliable evidence for designing and monitoring services and support."



TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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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, children, their families, and the dedicated people who work with this challenging population. The contents do not necessarily represent the official position of TARC.

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HELP TARC HELP FAMILIES – BECOME A MEMBER TODAY



Hispanic Parents Support Group
El Grupo Hispano de Apoyo a Padres de Familia

Next Meeting: Monday, February 26
7:00 to 8:30 p.m.
Martin Regional Library, 2601 S. Garnett
For information, call:
Zaida Castro-Kepford, 918-582-8272



Activities Group for Adults with Developmental Disabilities

Thursdays • 1:00-2:30 p.m.
McClure Recreation Center
7740 E. 7th Street in Tulsa
Contact: Amie, 918-582-8272



TULSA PEOPLE FIRST

Next Meeting:
Tuesday, Feb. 13

Meeting-5:00 p.m.
Dinner-6:00 p.m.

For information, call Amie at 918-582-8272

Asperger's Syndrome S.O.S.

A project of Tulsa Public Schools in conjunction with TARC

Next Meeting:
Thursday, February 1
6:30-8:00 p.m.
Kendall Whittier Elementary

S.O.S. is a social group for kids with Asperger's Syndrome and a support group for their parents, both of which are open to all families — not just those in Tulsa Public Schools.

To sign up, call Stephanie Orban at 746-8747. For more information, contact Sherilyn Walton at TARC, 918-582-8272.

Connections Asperger's Group

Next Meeting:
Wednesday, Feb. 28 - 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 Walton or Amie Farinella at 918-582-8272 for information.



Next Meeting:
Thursday, Feb. 22
7:00-9:00 p.m.

Kirk of the Hills Presbyterian Church, 4102 E. 61st St., Room B-8
Contact: Sherilyn Walton, 918-582-8272
• No child care provided

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 joy of raising our children.



Next Meeting: Tuesday, February 20
7:00 - 8:30 p.m.

First Baptist Church of Owasso, 13307 E. 96th Street North, Room 700
For more information, contact Sherilyn Walton at 918-582-8272.