

News from The Arc of Tippecanoe County, January 2014



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www.arcoftippecanoe.org

Executive Director Update

Happy New Year!

The Arc of Tippecanoe wishes all our members and friends a Happy New Year! The Holiday Dinner and Dance was wonderful with over 150 consumers, family members and volunteers attending. Thank you so much to the Carpenters, the Roberts, the Wilsons, Katy Dietrich and especially the Schwietermans for organizing, cooking and hosting the night. Our volunteers from local sororities, NSSLA, Best Buddies and the board provided great service and wonderful help with registration. Thank you to all for your help. Great food and fun was had by all! Cindy Roberts was honored as outgoing Board President and Katy Deitrich honored for her many years of service as a board member of The Arc. Katy is resigning from the board but will continue to lead Best Buddies for The Arc.

SuperStar Social Club Junior and Senior also had a great time at their Holiday Dinner and Dance. Thank you to the Carpenters, Julie Griffin and Emily Tyson-Studebaker and all the other great volunteers that made this event a fun and awesome night.

Aktion Club enjoyed their Christmas meeting and party hosted by Kiwanis and the new officers were presented. Congratulations to Chad Radcliff – President, Shawn Rector – Vice President, Chris Lowery – Secretary, and Brad Neff – Treasurer. Thank you to Ken and Gale Schwieterman and the Kiwanis Club for sponsoring this great service club for adults with disabilities.

The Arc Board of Directors held the annual retreat on November 2nd and celebrated this year's successes and began to strategically plan for the next three years. New officer's will take charge this week with Monica Doerr as President; Emily Studebaker, Vice President; Cari Carpenter, Treasurer; and Dan Carpenter, Secretary.

As Executive Director, I have been busy researching new grants and working on our current strategic plan, developing new marketing, development and volunteer plans which will allow us to enhance and expand our services in the upcoming year. The Arc can't provide all the wonderful activities, events, education and advocacy for children and individuals with disabilities and their families without our amazing volunteers. We

continue to need volunteers in several areas. Please see the list below and contact me to volunteer. Also if you have any ideas for grants or ways to increase donations, I would love to hear from you. Due to family medical issues I will be on leave during the month of January and not be in the office, but will be checking emails, attending to the Arc phone and working on some ongoing projects.

Please feel free to give me a call or send me an email with your thoughts and ideas for improving and enhancing Arc services and programs in 2014. I look forward to working with The Arc's talented and dedicated board, consumers, volunteers and membership this year! director@arcoftippecanoe.org 765-476-3277

Wishing you all a Happy and Healthy 2014!

Jennifer Meadows, Executive Director

The Arc Needs You!

There are many opportunities to volunteer with The Arc! Many of the activities can be done in your own home in your free time. Below are just a few of the areas in which The Arc needs volunteers:

- ✓ Serve on the Board of Directors or on a Committee
(Direct Services, Education, Fundraising, Membership)
- ✓ Volunteer to help with office work such as;
 - coordinate adult recreation event RSVPS.
 - update our membership and emergency contact forms
 - organize our event and outcome data
 - enter data into the computer
 - coordinate membership information and applications
 - copy needed documents
 - create flyers, brochures, news blasts, newsletters and news articles
- ✓ Volunteer to assist with events:
 - Spend an afternoon with some happy campers at Camp SPARKS next summer
 - Assist with Aktion Club as a presenter or organizer
 - Help staff fun Adult Recreation events such as bowling, Purdue games, Indiana Beach, dances and other great activities.
 - Sponsor or help supervise a SuperStar Social Club event for children with special needs.
 - Help staff our Parents Night Out program.
- ✓ Create this newsletter, or a better version!
- Create news "blasts", PSAs or updates to our consumers or membership

- Assist with fundraising
- Assist with marketing events and trainings

Let us know how you'd like to help:

765-476-3277 or director@arcoftippecanoe.org.

A BIG THANK YOU TO ALL WHO MADE GENEROUS DONATIONS TO THE ARC OF TIPPECANOE

The Arc of Tippecanoe recently completed our end of the year direct appeal for donations. We are excited to announce that we hit the \$2,000 mark. Thank you so much to the following families and individuals who generously donated this year.

Reed and Company

Charles Young

Andrew and Gail Mesecar

Malissa Crowe

Allyson and Alex Steselboim

W. Neal Carpenter

Floyd Crowe

Ron Clark

Ralph and Betty Green

Bob and Heather Gilbert

James and Christine Brewster

Joseph and Bette Rubinstein

MaryAnn Harrison

Ronald and Erika Steuterman *

Jack and Devi Nichols

Roberta Deagan-Kierce

Paul Draper

Thomas Brown

***A very special thank you to the
Steutermans for their gold star donation!!!**

Wabash Center is offering an afterschool program for children with special needs. The program will begin in January of 2014. For more information contact: Rhonda

Jones, Director of Development & Communications Wabash Center 765-423-5531 ext 353

Jan. 22nd - FREE Next Steps Workshop (Lafayette)

This Next Steps series is made available FREE OF CHARGE through the generous support of Kappa Kappa Kappa, Inc.

Registration is *required* for all seminars and workshops. Space is limited.

Next Steps is primarily designed for primary caregivers who have a child that has recently been diagnosed with an Autism Spectrum Disorder. However, this seminar may also be beneficial for other caregivers, educational or therapy professionals, and other adult family members. Individuals interested in this seminar do not need to be patients of Riley Hospital to attend. Please contact us at (317)274.2675 or hands@iupui.edu with any questions or concerns.

For more upcoming events in your area, please check out our entire list of events on [ARNI](#)

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Recent Major Events

Budget & Appropriations - Congress and the Administration Agree to a Bipartisan Budget Deal

On December 18, the Senate passed the Bipartisan Budget Act of 2013 (H.J. RES 59) by a vote of 64-36. The House of Representatives approved the legislation on December 12. This agreement will raise \$85 billion over the next decade by increasing pension contributions for newly hired federal workers, decreasing cost of living adjustments for military personnel, and raising air passenger travel fees. About \$62 billion of the revenue would go toward replacing part of the across-the-board spending cuts (sequestration) over the next two years. The easing of these spending cuts will be split equally between defense and non-defense discretionary programs (which include programs such as supportive housing, special education, and funding

for critical public health programs). The remaining \$23 billion would go toward deficit reduction.

While The Arc is pleased that the budget agreement is intended to prevent another government shutdown early next year and does not make major changes to our lifeline programs including Social Security, Medicaid, and Medicare, we are concerned about an expansion of the state Medicaid agencies' ability to recoup costs from settlements from Medicaid beneficiaries. This expansion could affect payments owed to individuals and families who have been harmed, received compensation, and depend on the compensation to pay for expenses beyond what Medicaid covers. Allowing a state Medicaid agency to recover "any payments" by a third party with legal liability (rather than just those payments for health care items and services, as under current law) would leave beneficiaries without coverage for other basic necessities, such as accessible housing or an accessible van.

The budget deal also includes a short term fix that will prevent scheduled cuts to Medicare providers. Legislation was needed to prevent the cuts from taking place on January 1, 2014. The House and Senate are both considering bills to permanently replace the problematic formula.

Autism - Deal on Defense Bill Drops Behavioral Health Therapy provision

A last minute agreement on a new Defense bill (H.R. 3304) negotiated by the Senate and the House dropped dozens of proposed amendments, including a provision to improve TRICARE coverage for military families. The provision would have covered applied behavioral analysis (ABA) for family members with autism and other developmental disabilities through the military's health care program (TRICARE). The effort to improve TRICARE coverage for behavioral health therapy will have to start over from the beginning in Congress next year, the third time since 2012.

Employment - New Report on Federal Employment of People with Disabilities

The Office of Personnel Management (OPM) has released its [annual report](#) on the employment of people with disabilities in the federal executive branch. By the end of FY 2012, total permanent federal employment for people with disabilities had increased from 203,694 in FY 2011 to 219,975, an increase from 10.97 to 11.89 percent. New hires who were people with disabilities totaled 16,653, an increase from 14.65 percent in FY 2011 to 16.31 percent in FY 2012. Full-time permanent employment by people with "targeted disabilities" ; (a category which includes intellectual disability and other significant disabilities) rose from 17,845 in FY 2011 to 18,319 in FY 2012. However, new hires who were people with "targeted disabilities" fell from 1,122 in FY 2011 to 1,101 in FY 2012. The Arc [strongly supports](#) increasing employment for people with disabilities, including within the federal government. While OPM's new report shows overall progress, the reduction in new

hires with “targeted disabilities” highlights the need for continued leadership and advocacy to realize the vision of the President’s goal of hiring 100,000 people with disabilities in 5 years ([Executive Order 13548](#), “Increasing Federal Employment of Individuals with Disabilities”).

Major Events Ahead

Budget and Appropriations - FY 2014 Spending Bills and Debt Limit Increase Expected to Take Center Stage in the New Year

The spending changes included in the Bipartisan Budget Act will not take place automatically. Congress must still pass appropriations bills before January 16, 2014, when temporary funding for the government under the current continuing resolution expires. The two appropriations bills that fund the vast majority of disability-related programs, the Labor, Health and Human Services, and Education bill (L-HHS-ED) and the Transportation and Housing and Urban Development (T-HUD) bill, may be continued at current spending levels for at least some time because both have recently encountered opposition in Congress. It will remain to be seen how specific [disability-related programs](#) such as supportive housing, special education, and supported employment ultimately fare in 2014. Now that the across-the-board spending reductions have been removed, these individual programs could see increases, decreases, or level funding.

There is also some concern that the need to raise the debt ceiling again in mid-February to early March may provide another threat to spending programs. Some Members of Congress may demand further spending cuts as a condition of raising the debt ceiling.

Health Care - HHS Allows People with Canceled Individual Plan Policies to Qualify for an Exemption

In another effort to help people who have had their health insurance plans canceled because the plan does not comply with the new consumer protections or other provision of the Affordable Care Act, HHS has created a new hardship exemption that will allow people to purchase catastrophic plans. Currently only Americans under age 30 and those with financial hardships are permitted to buy catastrophic plans sold on the exchanges. Catastrophic plans are usually cheaper because they offer only minimal insurance coverage. The Administration is estimating that about 500,000 people have had their policies canceled but have not found other coverage. The Centers for Medicare and Medicaid Services (CMS) is setting up a separate hotline (1-866-837-0677) to help consumers with cancellations. CMS is also trying to get the word out about [what options people](#) have when the policy is canceled.

Webinar January 22

Ticket to Work: Support for People with Disabilities on the Journey to Financial Independence

Some people with disabilities may be able to work and continue receiving disability benefits. On January 22, tune in to a free webinar from the Social Security Administration to learn about the Ticket to Work program and the path to financial independence. Get tips, tools, and resources that help you:

- Learn how to save what you earn
- Understand tax benefits that may apply to you
- Gain basic financial knowledge like budgeting and expense tracking

Ticket to Work: Support for People with Disabilities on the Journey to Financial Independence
January 22
3:00 pm to 4:30 pm ET
Register here: <http://fifthfreedom.org/u/he>

Indiana Governor's Council for People with Disabilities

COUNT US IN 2014 --- PUBLIC POLICY SEMINAR

- Are you an adult or senior with a disability or chronic condition, a spouse, parent, or other loved one of a child with a disability or chronic condition?
- Would you like to see a barrier free society where everyone is a valued member of his or her community?
- Are you interested in promoting change within the state, within the country?
- Would you like to improve your knowledge about public policy issues and your relationship with your legislators?

If you answered yes to these questions, you might be interested in applying for the Council's Public Policy Seminar.

During a full day seminar to be held on **Friday January 31, 2014** you will hear from Indiana organizations and lobbyists about the key issues before the Indiana

General Assembly and the United States. The seminar will help you understand the issues and how and when to advocate for those that are important to you. Following seminar participants will remain in touch with each other and with the lobbyists who will provide information on the progress of key legislation and opportunities to contact legislators, attend hearings.

Please contact the IGCPD for applications or visit their website. Applications are DUE JANUARY 10.

You will be notified that your application has been accepted and additional details will be provided via email after January 10.

Contact:

Governor's Council for People with Disabilities
402 W Washington St , Rm E-145
Indianapolis, IN 46204
317-232-7774; Fax 317-233-3712
cdahlberg@gpcpd.org

Revised autism screening tool offers more precise assessment

Testing during routine checkups indicates earlier diagnosis possible

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An updated screening tool that physicians administer to parents to help determine if a very young child has autism has been shown to be much more accurate than earlier versions at identifying children who could benefit from further evaluation, according to researchers supported by the National Institutes of Health.

The Modified Checklist for Autism in Toddlers — Revised, with Follow-Up (M-CHAT-R/F) — is a free, two-step screening tool used to detect children likely to have autism. It is intended for use at regular well-child checkups for children 16 to 30 months old. With the M-CHAT-R/F, health care providers can classify a child's risk of having autism as low, medium or high, on the basis of parents' answers to 20 questions.

"This checklist can more accurately identify children likely to have autism so they can get the treatment and support they need," said Alice Kau, Ph.D., of the *Eunice Kennedy Shriver* National Institute of Child Health

and Human Development (NICHD), the NIH institute that funded the study. “Given that the typical autism diagnosis occurs at age 4, it also offers the possibility of detecting autism much earlier – during regular doctor’s visits when a child is 18 months or 2 years old. And earlier intervention has been shown to improve outcomes for children with autism.”

A score in the high-risk range warrants a referral for further evaluation for possible autism. For a child determined to be at medium risk, M-CHAT R/F includes a follow-up questionnaire used soon after the original evaluation to obtain additional information needed to more definitively classify the child as either high risk or low risk.

Based on the M-CHAT-R/F classifications, the researchers found that a smaller proportion of children received a medium- or high-risk assessment (7 percent) than with earlier versions of the checklist (9 percent). However, more total cases of autism were detected with the revised checklist than with earlier versions (67 cases per 10,000 screened vs 45 cases per 10,000 screened).

Of the more than 16,000 children evaluated with the screening tool, 93 percent of the children screened were considered low-risk, 6 percent were in the medium-risk range and 1 percent were considered high-risk.

Of all the children who determined by the test to be at risk after the M-CHAT-R/F follow-up, 95 percent were eventually found to have some form of developmental delay, including more than 47 percent with autism spectrum disorder.

First author Diana L. Robins, Ph.D., of Georgia State University (GSU), in Atlanta, conducted the research with GSU colleague Karis Casagrande, and Marianne Barton, Ph.D., Chi-Ming Chen, Ph.D., Thyde Dumont-Mathieu, M.D., M.P.H., and Deborah Fein, Ph.D., all of the University of Connecticut in Storrs. Dr. Fein was the study’s senior author.

The findings appear in *Pediatrics*.

The researchers updated an earlier version of the autism screening tool, adding examples, rephrasing some questions and dropping others that previously did not elicit strong responses. Using the revised tool, the researchers worked with health care providers to screen more than 15,000 toddlers considered at low risk for autism.

“Earlier tools cast a wider net, but these refinements will allow health care providers to focus energy where it is needed most and will reduce the number of families who go through additional testing but which ultimately do not need treatment interventions,” said Dr. Fein.

The free [autism screening tool](#)  is available online in more than 45 languages.

This study was supported by NIH grant number R01HD039961.

About the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD):

The NICHD sponsors research on development, before and after birth; maternal, child, and family health; reproductive biology and population issues; and medical rehabilitation. For more information, visit the Institute's website at <http://www.nichd.nih.gov/>.

About the National Institutes of Health (NIH): NIH, the nation's medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov

Calendar of Events: Check out our upcoming events!!!

SuperStar Social Club Sr.

January Event TBA

Contact Julie Griffin at jgriffin@tsc.k12.in.us for more information.

Aktion Club

Meets the third Thursday of the Month 4:30-5:30.

Contact Jennifer Meadows at director@arcoftippecanoe.org for more information or call The Arc office.

SuperStar Social Club Jr.

January Event TBA

Contact Camille Rocroi at crocroi@lsc.k12.in.us for information.

Adult Recreation:

January Event TBA

For more information contact: director@arcoftippecanoe.org or call The Arc office.

Please let us know if you have an address change.

Best Buddies

January Event TBA

Unless notified otherwise, all Best Buddies events are at DLR, 207 South Martin Jischke Drive, West Lafayette

Contact Katy Dietrich at 765-420-2957 or email katy@gocitybus.com for more information.

The Arc website has been updated! Check it out at www.arcoftippecanoe.org

Pictures on Facebook

Have you visited our [Facebook](#) page lately? Lots of great pictures from recent activities have been posted!

Opportunity for Input

Survey for Children ages 18 months to 8 years of age who have a Diagnosis of Autism Spectrum Disorder in Lafayette and surrounding areas, and Bloomington and surrounding areas.

Survey for families in Lafayette area:

<https://redcap.uits.iu.edu/surveys/?s=vWQyEk3taG>

Survey for families in Bloomington area:

<https://redcap.uits.iu.edu/surveys/?s=YahjtBpxVV>

If you would prefer a paper copy, please contact Angela

Paxton: 317.278.3435 (phone) 317.278.0456 (fax), email: arpaxton@iu.edu

Each year IPAS solicits input from the public which is used to help determine how IPAS spends its resources and efforts for the next year. Please help identify critical barriers that IPAS should consider as priority areas for our advocacy efforts - barriers that you believe, if eliminated or reduced, would benefit people the most.

Please help us by taking a few minutes to complete the 2013 Disability

Critical Barriers Survey.

For more information or to request an alternate format, contact Matt Norris at the Indiana Institute on Disability and Community at 1-800-825-4733 or cpps@indiana.edu

<http://www.iidc.indiana.edu/cpps/survey/>

The Arc is seeking caregiver views of the health status of the people with intellectual and developmental disabilities (I/DD) they support. If you or someone you know is a professional, paid, unpaid or family member caregiver of someone with I/DD, we invite you to take a short, confidential [online assessment](#) to help us collect valuable information about caregiver views of the health status of people with I/DD.

In exchange, you can use the assessment as a tool to help you evaluate any “red flag” health concerns you may have about the people for whom you provide care. While this checklist should not be used in the place of seeing a doctor, it can be a handy way to identify concerns.

Questions? Please contact Jennifer Sladen at sladen@thearc.org.

Reminder!!! Arc of Tippecanoe County memberships are now free and entitle members to email news blasts, Arc of Indiana newsletters, news on upcoming trainings, events and more! For more information, check the Arc of Tippecanoe website at www.arcoftippecanoe.org or email Kathy Trinkle at membership@arcoftippecanoe.org

Thank you to all our Arc members for your support during 2013!

The Arc of Tippecanoe Board of Directors 2014

Monica Doerr: President

Emily Tyson-Studebaker: Vice-President

Dan Carpenter: Secretary

Cari Carpenter: Treasurer

Directors: Jennie Churchwell, Jeff Neff, Cindy Roberts, Julie Griffin, Scott Micklo, Camille Rocroi, Nurit Harash-Kantor

Executive Director: Jennifer Elliott Meadows, director@arcoftippecanoe.org