



Educating, Assisting, Supporting, and Informing through this newsletter...
A newsletter for and by parents with sons & daughters with disabilities and education advocates.

Families Together, Inc.

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Volume 93

Summer 2012

Health Care Reform Law Upheld, Medicaid Expansion Weakened

Family Voices, June 29, 2012

The U.S. Supreme Court finally announced its ruling on the constitutionality of the landmark health care reform law, the Affordable Care Act (ACA). Chief Justice John Roberts wrote the opinion, upholding most of the law, which was joined in various combinations of other Justices on the different issues under consideration.

Individual mandate. The biggest issue of the case was "individual mandate" of the ACA - requiring most people to either have health insurance or pay a penalty. The Court had been expected to judge whether this key provision of the law was constitutional based on the "Commerce Clause" of the Constitution, which gives Congress the power to regulate interstate commerce and is the basis for civil rights laws and numerous other acts of Congress. Indeed, the Court found that the individual mandate *did* exceed Congress' power under the Commerce Clause. But then the Court delivered a surprise: they deemed that the "penalty" for failure to have insurance is a "tax" that Congress was constitutionally authorized to impose under its taxing power. This legal theory had been offered by the U.S. Solicitor General (government's lawyer before the Supreme Court) as a back-up justification for the law. Interestingly, the Court determined that the "penalty" was *not* a tax for purposes of the Anti-Injunction Act, under which a court cannot consider a case that challenges a tax until the tax has been collected, which in this case would be April 2015.

Medicaid expansion. The Court decided the ACA's expansion of Medicaid to cover all individuals with incomes below 133% of the Federal Poverty Level (FPL) (effectively 138% of the FPL due to a disregard of 5% of income). The penalty for a state's failure to comply with a Medicaid mandate is withholding *all* of the state's Medicaid matching funds (although this sanction has never been imposed). The Court found that this penalty was so drastic -- since the federal match is such a large portion of state budgets - essentially, forcing states to adopt the expansion. Thus, the Court deemed the Medicaid provision to be an unconstitutional "coercion" of states, violating the principle of federalism reflected in the Tenth Amendment to the Constitution (which reserves for the states powers that are not given to the federal government).

Instead of striking down the expansion, however, the Court decided that the law could be made constitutional by invalidating the penalty for noncompliance. This apparently leaves the federal government without recourse if a state does not cover the new "mandatory" eligibility group.

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In addition, it appears that, in states that do not cover the expansion population, some or all of the people with incomes below 133% of (FPL) will be unable to get subsidies to purchase insurance. The ACA assumed those people would be covered by Medicaid so did not provide premium subsidies for them.

The Medicaid expansion was estimated to make about 17 million more people eligible, more than half of the 30+ million that are expected to gain coverage under the ACA. This population is primarily low-income, childless adults, and may include some people with disabilities who do not get Medicaid on some other basis, such as those who can work but have jobs that do not offer insurance coverage.

It is possible that the Department of Health and Human Services (HHS) find ways to encourage the states to adopt the mandate, and/or invoke less drastic measures to enforce compliance, thus eliminating the "coercion" factor. Moreover, many states will likely adopt the expansion anyway. There is likely to be pressure to do so from providers who serve large numbers of uninsured patients, and it is a good deal for states -- the federal government pays 100% of the cost for covering the new population in the first three years (2014 through 2016), gradually decreasing the federal share to a 90% match beginning in 2020. That said, governors and experts have varying predictions about how many states will adopt the expansion.

Other provisions. Experts seem to agree that the Court's decision on the Medicaid eligibility expansion does not threaten the ACA's maintenance-of-effort provision, which requires states to maintain (until 2014 for adults and 2019 for children) their Medicaid and CHIP eligibility levels and processes in place on March 23, 2010, when the ACA was enacted. The ruling also does not seem to jeopardize the provision (effective January 2014) allowing former foster children to qualify for Medicaid until age 26. Since Chief Justice Roberts made a point of distinguishing the ACA's Medicaid expansion from other Medicaid mandates, it does not appear that HHS has lost its enforcement power with respect to other provisions of the Medicaid program.

Repeal? Republican leaders in Congress have vowed to seek repeal of the ACA. After the election, though, the ACA could be in peril. If the House, Senate and White House are all Republican-controlled, the chance of repeal is significant. If the House and White House are Republican-controlled, and the Senate has only a slim Democratic majority, it is also possible for a repeal measure to advance under certain circumstances.

A Note From the Director's Desk...



Dear Parents and Education Advocates:

The summer is flying by and the staff here at Families Together is busy updating training and planning events for you and your family for the next school year. I hope that you will consider attending a conference, a Step-by-Step Event to support services, or call for information to support the needs of your son or daughter. Watch for information about upcoming events across the state.

Parents and Appointed Advocates are SO important to the success of students in school and in our communities. The engagement of a trusted adult in the lives of children and young adults can be what makes or breaks their lives for years to come. If you are an appointed advocate, summer can be a good time to see the child you are advocating for in a different setting. By knowing their interests, you can become a better spokesperson for them in the IEP meetings for the 2012-13 school year. Families Together staff members are ready to help you understand your vital role. Call or come by our offices to learn more. We have many materials and tools for you to use.

Would you like to talk to another parent facing similar challenges? Call our offices for a Parent to Parent match! It can be great to talk to another parent about the concerns that you have and share the little joys that we, as parents, can appreciate!

Enjoy the rest of the summer. Hope to see you at a conference in the next school year.

Connie

ABLE Act Achieving a Better Life Experience

From Real Economic Impact, a vision of the National Disability Institute

The U.S. Congress took a historic step on November 15, 2011 for Americans with disabilities by reintroducing the Achieve a Better Life Experience (ABLE) Act, legislation long championed by the National Disability Institute and other disability organizations as a key to providing a pathway to a better economic future for persons with disabilities and their families.

With bipartisan support, Rep. Ander Crenshaw (R-FL) in the U.S. House of Representatives and Sen. Robert Casey (D-PA) in the U.S. Senate reintroduced the ABLE Act in 2012 (as H.R. 3423 and S. 1872, respectively) in an effort to encourage and assist individuals with disabilities and their families to set funds aside in a tax-advantaged savings account that allows the funds to be withdrawn to cover costs of health care, employment support, housing, transportation, the purchase of technology and lifelong education. The funds will supplement but not replace benefits provided through Medicaid, Social Security and private insurance, allowing families with sons or daughters with significant disabilities a means to provide for extra costs associated with every day activities and community participation. The income earned on amounts contributed to an ABLE Account would be tax exempt and not counted as part of any asset limits for eligibility to federal programs.

National Disability Institute supports the passage of the ABLE Act and continues to promote public policy changes that encourage work, saving, and asset development for people with disabilities and that reduce dependence on public benefits. The ABLE Act was introduced originally in the 111th Congress and had more than 200 cosponsors in the House and 25 in the Senate. Time ran out before Congress moved the legislation forward.

We need your help!

Please call your two Senators and U.S. Representative. Let them know how this act would affect your family. If you support the bill, ask them to be an original cosponsor of the ABLE Act of 2011.



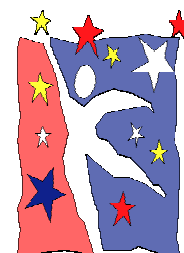
Welcome!

Families Together Inc. welcomes Klondy Nelson to the Wichita Parent Center. Klondy will be responsible for coordinating our Parent to Parent program, facilitating a newly developed parent support group, and assisting families in need of encouragement, education, and empowerment.

Before joining our team, Klondy was actively involved in multiple volunteer positions as well as raising her two boys, Bryce and Parker. Her youngest son Parker was diagnosed with ADHD and High Functioning Autism two years ago when he was in first grade. Since that time, Klondy and her husband of eighteen years, James, have devoted themselves to being the best parents possible to their exceptional child as well as their typical one. Klondy is passionate about helping other families get the help and support they need not just to survive but to thrive!

Klondy is available to assist you Monday, Tuesday and Wednesdays during the summer months.

Education Advocate Update



We hope your summer has been relaxing and enjoyable! We'd like to thank the many education advocates who sent in their surveys-- they are so helpful to us as we plan for the upcoming school year. We have received current information on 558 students this summer from either the education advocate or the student's case manager. It is our goal to have current placement and school information on every student in the program. This ensures that kids are matched to an education advocate appropriately. If you still have a survey laying around, please complete it and send it in!

The start of school is just around the corner. You may wish to arrange to meet with your student's teachers and explain your role. Often times, part of our role is to educate others about the rights of an education advocate. Understand that many teachers have never had the opportunity to work with an education advocate. Remember that you have the right to visit the school and observe your student in the classroom. You may want to attend parent-teacher conferences. If your student doesn't live with you, it may be necessary to arrange a communication schedule as well. Education advocates need to stay on top of the child's progress in order to effectively do our job.



Family Story

Thirty-eight year old Austin Hanson is a three time US Paralympian. He was born in Topeka, Kansas on January 4, 1974. Shortly after birth, it was discovered that Austin had a birth defect of his esophagus. His esophagus was blind (the upper portion was not connected to the lower portion) and it was connected to his trachea. Surgery was needed to correct it. His first surgery was preformed less than 24 hours later. The next three months brought a roller coaster of life threatening episodes including aspiration and respiratory arrest that lead to the discovery of a second connect (double TE Fistula) between the esophagus and trachea. Corrective surgery was preformed but Austin's trachea collapsed and his heart stopped. The cardiac arrest resulted in severe cerebral palsy. The doctors at Children's Mercy Hospital said that Austin's type of birth defect is very rare with the odds of one in a billion.

With a dynamic smile and zest for life, this one in a billion guy has gone on to endure 48 surgeries and several Evil Knievel stunts in and out of his power wheelchair.

Austin continues to live in Topeka near his parents Gary and Marie Baraclough. He has one sister Kristy Feuerbacher. Kristy and her husband, Travis, have given Austin two nieces and one nephew to spoil. The kids have re-named Austin "Unky" (short for uncle). Most of Austin's time is now spent with his significant other Kristeen Frost. She captured his heart a year ago and he hasn't stopped smiling since.

Austin has been receiving services such as case management, self-determination, assistive technology from TARC in Topeka for the past 20 years. The assistance he has received has made his ability to manage his daily life much easier.

Austin attended Capper Foundation in Topeka and graduated from Seaman High School in 1993. Austin has been employed at Families Together Inc. for the past 17 years. As a Data Entry Operator and the only man in the office, he has learned to keep plenty of chocolate at his desk for his female coworkers. His entrepreneurial spirit has led him into several business ventures. The latest being an accessible surrey bicycle business. He was the recipient of the 2006 Peter John Loux Award for overcoming challenges and achievements.

Pro tennis and college basketball are Austin's favorite sports. He enjoys a good love story and comedies. Next to playing Boccia Ball, music is his passion. He is extremely social, despite his lack of a voice and hard to understand speech. Austin doesn't allow any of that to get in his way, though. His sparkling blue eyes and his shining smile have served him well as he maintains friendships around the globe.

The summer of 2011 was exciting. Austin was named to the list of the top 100 athletes to ever come out of Shawnee County, Kansas (third largest county). The list consisted of athlete's records dating back into the 1800's. Mike Torrez topped the Top 100 Athlete's list. He was a pitcher for the New York Yankees. Melvin Douglas, a two time Olympian with one World Title, came in third. There were many other great athletes on the list and among them was Austin. He was named 43rd and was the only Paralympian or athlete with a disability on the list.

Austin started playing Boccia Ball at the age of twelve. Boccia Ball has evolved from a sport that he didn't like to a passion that has consumed his life for the past twenty-six years. He has trained hard, practicing at a local YMCA three to five hours a day to maintain a position in the top 25 in the world.

Austin has won ten National Championships in 96, 97, 2000, 04, 05, 06, 08, 09, 10, 11, with three second place finishes in 98, 99, and 07. He has competed in two Paralympic Trials in 1996 and 2004 winning both of them, three America's Cups in 2002, 05, and 09, four World Championships in 98, 02, 06 and 10, and four World Cups, in 99, 03, 07 and 11. He finished 5th in individuals in the 1996 Paralympics in Atlanta, Georgia. At the 2004 Paralympics in Athens, Greece, Austin was a quarter finalist. His most recent medal came in 2009 at the America's Cup in Montreal Canada where he placed third and received a bronze medal.

Austin is looking forward to representing the United States as part of the US Paralympic Team as he goes for the gold in London this August.



La Ley de Reforma de Cuidado de Salud Confirmó, la expansión de Medicaid se ha debilitado

Family Voices, 29 de junio, 2012

La Corte Suprema de los EE.UU. anunció finalmente su fallo sobre la constitucionalidad de la ley de salud histórica reforma de la atención, la Ley de Asistencia Asequible (*siglas en inglés, ACA*). Presidente del Tribunal Supremo, John Roberts, escribió la opinión, confirmó la mayor parte de la ley, que fue acompañado en varias combinaciones de otros jueces sobre los diferentes temas bajo consideración.

Mandato individual. El asunto más importante del caso era "mandato individual" de la ACA - que requiere la mayoría de las personas tener un seguro de salud o pagar una multa. El Tribunal se había previsto para juzgar si esta disposición clave de la ley era constitucional basándose en la "Cláusula de Comercio" de la Constitución, que le da al Congreso la facultad de regular el comercio interestatal y es la base para las leyes de derechos civiles y numerosos otros actos del Congreso. En efecto, el Tribunal consideró que el mandato individual superó el poder del Congreso bajo la Cláusula de Comercio. Pero entonces, la Corte dictó una sorpresa: se considera que la "multa" por no tener un seguro es un "impuesto" que el Congreso fue autorizado para imponer bajo su poder imponiendo contribuciones constitucionalmente. Esta teoría legal había sido ofrecida por el Procurador General de EE.UU. (abogado del gobierno ante la Corte Suprema de Justicia) como justificación de respaldo a la ley. Curiosamente, la Corte determinó que la "multa" no era un impuesto a los efectos de la Ley contra la medida cautelar, en virtud de que un tribunal no puede considerar un caso que desafía a un impuesto hasta que el impuesto que se ha recogido, que en este caso sería abril 2015.

Expansión de Medicaid. La Corte decidió la expansión de la ACA de Medicaid para cubrir todos los individuos con ingresos por debajo del 133% del Nivel Federal de Pobreza (*siglas en inglés FPL*) (eficacia del 138% de lo debido a un descuido de un 5% de los ingresos de FPL). La multa a los Estados por no cumplir con el mandato de Medicaid es la retención de la totalidad de los fondos estatales de Medicaid a juego (aunque esta sanción no ha sido impuesta). El Tribunal consideró que esta pena fue tan drástica - ya que el emparejamiento federal, es como grande parte de los presupuestos del Estado - en esencia, lo que obliga a los Estados a adoptar la expansión. Por lo tanto, la Corte consideró que la prestación de Medicaid a ser una inconstitucionalidad de la "coacción" de los Estados, violando el principio del federalismo se refleja en la Décima Enmienda a la Constitución (que se reserva para las competencias de los Estados que no se le da al gobierno federal).

En lugar de golpear a la expansión, sin embargo, la Corte decidió que la ley podría ser constitucional, al invalidar la sanción por incumplimiento. Esto, aparentemente, abandona el gobierno federal sin recursos si el estado no cubre el nuevo "obligatoria" elegibilidad del grupo.

Además, parece que, en los estados que no cubren la población de expansión, todas o algunas de las personas con ingresos por debajo del 133% de (*siglas en inglés FPL*) no podrán obtener subsidios de adquirir un seguro, la ACA asumido esas personas estarían cubiertas por Medicaid solo que no proveyeron subsidios primas para ellos.

La expansión de Medicaid se estima que cerca de 17 millones de personas más elegibles, más de la mitad de los 30 + millones se espera obtener la cobertura de la (*siglas en inglés ACA*). Esta población es mayoritariamente de bajos ingresos, adultos sin hijos, y pueden incluir a algunas personas con discapacidad que no reciben beneficios de Medicaid sobre otras bases, tales como aquellos que pueden trabajar, pero tienen empleos que no ofrecen cobertura de seguro. No todo está perdido, sin embargo. Es posible que el Departamento de Salud y Servicios Humanos (*siglas en inglés HHS*) pueden averiguar la manera de animar a los Estados a adoptar el mandato, y / o invocar medidas menos drásticas para hacer cumplir, eliminando así la "coerción" factor. Por otra parte, muchos estados es probable que adopte la expansión de todos modos. Es probable que sea la presión de los proveedores que sirven a un gran número de pacientes sin seguro médico, y es una muy buena oferta para los estados - el gobierno federal paga el 100% del costo para cubrir la nueva población en los primeros tres años (2014 hasta el 2016), disminuyendo gradualmente la participación federal en un principio compartiendo el 90% emparejamiento empezando el 2020. Dicho esto, los gobernadores y los expertos tienen diferentes predicciones sobre el número de estados que adoptan la expansión.

Otras provisiones. Los expertos parecen coincidir en que la decisión del Tribunal sobre la expansión de la elegibilidad para Medicaid no amenaza a la (*siglas en inglés ACA*) de mantenimiento del esfuerzo de disposición, que obliga a los Estados a mantener (hasta el año 2014 para los adultos y 2019 para los niños) a su Medicaid y los niveles de elegibilidad de CHIP y procedimientos a fin del 23 de marzo de 2010, cuando se promulgó la (*siglas en inglés ACA*). El fallo también no parece poner en peligro el suministro (a partir de enero del 2014) lo que permite ex niños de crianza temporal para calificar para Medicaid hasta los 26 años. Y, como Presidente del Tribunal Supremo Roberts hizo un punto de distinguir la expansión de la (*siglas en inglés ACA*) de Medicaid de otros mandatos de Medicaid, no parece que el

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(siglas en ingles HHS) ha perdido su poder de ejecución con respecto a otras disposiciones del programa de Medicaid.

¿Revocar? Los líderes republicanos en el Congreso se han comprometido a buscar revocar la (siglas en ingles ACA). Después de la elección, sin embargo, (siglas en ingles ACA) puede estar en peligro. Si la Cámara, el Senado y la Casa Blanca están controlado por los republicanos, la posibilidad de revocacion es significativo. Si la Cámara de Representantes y la Casa Blanca son controlado por los republicanos, y el Senado sólo tiene una pequeña parte de mayoría demócrata, también es posible que una medida de revocacion para avanzar en determinadas circunstancias.

Kaw Valley Rodeo

The Kaw Valley Rodeo Association will be sponsoring the 19th Annual Kaw Valley Special Rodeo for children with special needs. Children, ages 5 to 12 years old are invited to sign up for it. It will be held Friday, July 27, 2012, at the Riley County Fairgrounds, Wells Arena, Manhattan Kansas. The time will be 7:00 p.m. The special rodeo pairs up children with pro-rodeo "partners" who assist in fun and noncompetitive rodeo activities. All events are designed to be appropriate to the children's needs and accommodations are made for those with wheelchairs, crutches or braces. This is the 19th year it will be held.

There is no cost to the children, but due to the limited number of participants, pre-registration is required. For more information or to sign up your child, contact Sandy Chandler, 785-313-3863 after 5:00 p.m. or email to schandle@k-state.edu by July 20th.



Books to Read



Managing a Special Needs

Trust: A Guide for Trustees, 2012 Edition is now available at www.disabilitiesbooks.com as is **Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew**.

Families Together, Inc. receives a share of the proceeds (\$4/book) on the sales of these fine books whenever online buyers enter "FTI" in the Customer Comments space at the end of the order or write "FTI" on their checks when ordering by mail (DisABILITIESBOOKS, 44 Washington Street, #913, Brookline, MA 02445). Information about each book at the website includes a Summary, Table of Contents, Excerpts, Reviews, and Meet the Authors.

Managing a Special Needs Trust has received wonderful reviews from the Academy of Special Needs Planners, parents, and attorneys. An Arizona attorney wrote "...wonderful book written in language that is easy to understand...answers the majority of the questions that my clients have...It saves me hours of time answering their questions"

Reviews of Reflections by parents like Patricia McGill Smith ("...parents everywhere need to read this book...") and Judy Woodruff ("...I want every parent...to read this remarkable eye-opening book.") can be read in full at the website.

DisABILITIESBOOKS, Inc, is very appreciative of the marketing assistance of Families Together and congratulates Families Together on the 30th Anniversary of its important services to parents and professionals in Kansas.

www.disabilitiesbooks.com

Your Questions Answered!

Q. What is the timeline for the general education intervention process?

A. There is no rule of thumb for a timeline. The area(s) of concern and the nature of the interventions attempted will be the determining factors. The team will develop a plan that includes a timeline appropriate for each student. If it appears that the child's needs require interventions that involve intense or sustained resources beyond those available in the general education environment, and if the team suspects the child may have an exceptionality, the team must make a referral for an initial evaluation.

Q. If a child with a disability is sent home for part of a day is it considered a suspension?

A. Yes. Any time a child is removed from school as a disciplinary action without educational services this would be considered a suspension. Any part of a day is considered a whole day of suspension.

RESOURCES



FAMILIES TOGETHER TOLL FREE NUMBERS:

Wichita	1-888-815-6364
Topeka	1-800-264-6343
Kansas City	1-877-499-5369
Garden City	1-888-820-6364
Spanish line	1-800-499-9443

www.familiestogetherinc.org

MAKE A DIFFERENCE INFORMATION NETWORK

1-800-332-6262

An information service for children and adults with disabilities, their families, and their service providers.

www.makeadifferenceks.org

KPIRC

Kansas Parent Information Resource Center
(A resource for parents of any child)

3500 SW 10th Room 011E • Topeka, Kansas 66604
785-783-2975 • e-mail: jgroff@kpirc.org
website: www.kpirc.org

NICHCY

*National Information Center for
Children and Youth with Disabilities*

NICHCY Website
www.nichcy.org

- ★ All text-only publications have been reformatted to a new easy-to-read layout
- ★ A side-bar menu makes navigation easy
- ★ The ALL-NEW resource library featuring the Technical Assistance & Dissemination (TA&D) Network makes finding information a breeze

Call us or visit
our website!

1-800-695-0285
www.nichcy.org

Check out these Websites!



What You Need to Know about IDEA 2004: IEPs for Children with Behavior Problems

by Pat Howey, Paralegal and Advocate

[www.wrightslaw.com/howey/
iep.special.factors.htm](http://www.wrightslaw.com/howey/iep.special.factors.htm)

All about the IEP

<http://nichcy.org/schoolage/iep>

Getting Ready for School – Transition Tips

[www.paulakluth.com/readings/autism/getting-
ready-for-school/](http://www.paulakluth.com/readings/autism/getting-ready-for-school/)

Getting Ready for Middle School: Organizational, Time Management and Studying Skills

[http://onedublin.org/education-resources/getting-
ready-for-middle-school-organizational-time-
management-and-studying-skills/](http://onedublin.org/education-resources/getting-ready-for-middle-school-organizational-time-management-and-studying-skills/)

Back-to-School Tips for Parents of Children with Special Needs

www.readingrockets.org/article/38405/

Tips for students with disabilities to increase college success

[www.washington.edu/doit/Brochures/
Academics/survival.html](http://www.washington.edu/doit/Brochures/Academics/survival.html)

Understanding Bullying and Its Impact on Kids with Learning Disabilities or AD/HD

[www.greatschools.org/special-education/
health/823-understanding-bullying-and-its-
impact-on-kids-with-learning-disabilities-or-ad-
hd.gs](http://www.greatschools.org/special-education/health/823-understanding-bullying-and-its-impact-on-kids-with-learning-disabilities-or-ad-hd.gs)

Walk a Mile in Their Shoes: Bullying and the Child with Special Needs

[www.abilitypath.org/areas-of-development/
learning--schools/bullying/articles/walk-a-mile-in-
their-shoes.pdf](http://www.abilitypath.org/areas-of-development/learning--schools/bullying/articles/walk-a-mile-in-their-shoes.pdf)

Summer Calendar of Events

Date	Event	Contact
July 21, 2012	Families Together Family Fun Day, Kansas City	877-499-5369
Sept. 8, 2012	Families Together Step by Step Walk, Wichita	888-815-6364
Sept. 13-15, 2012	Families Together Trainer of Trainers, Wichita	888-815-6364
October 5-6, 2012	Families Together Spanish FEW, Garden City	888-820-6364
October 8, 2012	Families Together TEC, Wichita	888-815-6364
October 20, 2012	Families Together Transition TEC, Liberal	888-820-6364
November 3, 2012	Families Together Holiday Extravaganza, Garden City	888-820-6364
November 10, 2012	Families Together Pilgrim Pacer Run, Kansas City	877-499-5369

Austin Hansen is going for the gold in London this year. If you would like to help with expenses, donations can be sent to: Capital City Bank, 2040 NW Topeka Blvd., Topeka, KS 66608, 785-274-5600. Checks may be made out to: Austin Hansen's US Boccia Fund.

Return Service Requested

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