



DANNA MCKITTRICK, P.C.  
ATTORNEYS AT LAW

# Planning for the Future

2013 Special Needs Community Newsletter

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## Must-Have Documents If You Have a Child With Special Needs

No one lives forever, and for the parent or guardian of a child with special needs, the task of planning for the child after the caregiver's death becomes even more important. Thinking about someone else providing the care and love for your child may be difficult, but by maintaining important information and documents about children with special needs, parents and guardians can better prepare future caregivers.

Parents or guardians may make a binder with this information, or store it all in a safe with other important documents. Either way, this information should be placed in a location accessible to the future caregiver.

### Important Documents to Place in Safe-Keeping

1. Child's legal documents, e.g., birth certificate, health insurance cards, and social security card.
2. Parent(s) or guardian's legal documents, e.g., living trusts, special needs trusts, wills, living wills and powers of attorney.
3. List of parent(s) or guardian's assets, including access information (e.g., passwords to access online accounts). Include policy information as well as brokerage information on any IRA, 401(k), life insurance, bank accounts, mutual funds, or other assets to minimize the cost and difficulty involved in making these assets available to the child.

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### News on the FMLA:

## Clarification for Employees Who Are Parents of Adult Children with Disabilities

On January 14, 2013, the Department of Labor issued additional guidance to help employers determine an employee's eligibility to take leave under the Family and Medical Leave Act (FMLA) for a serious health condition of an employee's adult child with a mental or physical disability that makes the child incapable of self-care.

For more information, read Misty Watson's blog post at [http://bit.ly/maw\\_fmla\\_2013](http://bit.ly/maw_fmla_2013)



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# Lessening the Stress of Travel for Travelers with Disabilities

Flying can be a frustrating experience for anyone, but for those with disabilities it is even more difficult. Knowing what rights a passenger with disabilities has is the first step to ensuring the next flight is as stress-free as possible.

## Booking a Flight

When booking a flight, travelers with disabilities are generally not required to provide pre-flight notification with a few exceptions:

1. Traveling by stretcher;
2. Using an electronic wheelchair (or other device with special batteries); or
3. Requiring connection to the airplane's oxygen system during flight.

If none of these categories apply, the airline cannot deny travel for not being informed of a passenger with a disability's travel plan. However, notifying the airline may ensure any desired accommodations are met with less stress on the day of travel.

## Travel With an Attendant

Each airline determines whether an attendant is required, except in the following situations, which always require an attendant:

1. Passengers who cannot comprehend or respond appropriately to safety instructions,
2. Passengers with severe mobility issues who cannot assist in their own evacuation from the aircraft, and
3. Passengers with both severe hearing and vision impairment that make it impossible to receive safety instructions.

When an airline determines a traveler needs an attendant, it is not required to supply one. The airline can appoint an off-duty staff member on the flight to serve as an attendant or ask another passenger to volunteer to assist.

If the traveler and the airline disagree over the need for an attendant, the airline can require one but cannot charge for transportation of the attendant. Travelers with disabilities may also consider getting a letter from a licensed medical provider stating that they are capable of performing the necessary functions if there is any concern about the airline requiring an attendant.

## Medical Certificate

Generally a medical certificate is not required. However, there are exceptions and reasons why carrying a medical certificate may be a good idea. An airline may request a medical certificate if the traveler is on a stretcher or incubator, needs medical oxygen during the flight, or has a medical condition that causes the airline to have reasonable doubt that the person can complete the flight safely without extraordinary medical assistance. ACAA language leaves a lot up to airline personnel discretion. If concerned, the traveler with disabilities should get a medical certificate to avoid being denied the right to fly.

## Airport Escort and Service Animals

Passengers with a disability may have an escort take them through security and to the gate if desired. The escort gets a permit from



***Federal law has made provisions for people with disabilities who want to travel by airplane through the Air Carrier Access Act (ACAA) of 1986. The ACAA required the Department of Transportation to develop regulations to ensure non-discriminatory treatment of travelers with disabilities. Note: while travelers with disabilities do have accommodations for air travel under the ACAA, they are not required to accept any or all accommodations.***

the ticket counter to pass through security. Security screenings should be the same as for any other passenger, with a few exceptions. Individuals who are not physically capable of standing and raising their arms at shoulder level for five-seven seconds, are unable to stand without the aid of a crutch, walker, etc., have a service animal, or use oxygen will be screened using alternative measures (e.g., pat-downs). If a private screening is requested, it must be provided in time for the traveler to make the flight.

Once through security, travelers with disabilities and their escorts may move freely about the terminal. The personnel at the gate are required to give all the information available to other passengers to these travelers as well. Trained staff must be available to aid travelers with disabilities on and off the plane if needed. By being proactive and informing personnel that a person with disabilities is on the flight, and the accommodations needed, the airline can ensure the traveler's needs are met. In addition, the traveler is made aware of any information that may affect travel.

Once on the plane, seating cannot be made on the basis of disability, with the exception of FAA requirements for exit rows. Service animals must be permitted on board; however, animals may be placed in cargo if there is no safe place to put them on the flight. Airline personnel must help passengers with disabilities move around the cabin while onboard (e.g., to the restroom), open food/beverage containers as needed, and load/retrieve baggage.

## Refusing Travel on an Airplane

To ensure a smooth trip for travelers with disabilities, it is important to both know their rights and to be proactive in exercising these rights. While travelers cannot be denied travel due to disability, they can be denied travel if their presence on the flight would endanger others. Airline personnel can refuse

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## Special Education News Briefs

### St. Louis County Voters Pass Tax Levy Increase for Special School District

On November 6, 2012, St. Louis County voters approved Proposition S, which increases the operating tax levy to fund education for children with disabilities in the Special School District of St. Louis County. Proposition S also provides funds to expand job training and placement, improve safety, and repair, expand, furnish and equip schools, as well as rebuild one school.

Proposition S increases the operating tax levy by 19 cents per \$100 in assessed valuation, bringing the levy to a total of \$1.19 per \$100 in assessed value. Proponents of Proposition S estimate it will generate \$40 million for the Special School District of St. Louis County.



The Special School District of St. Louis County employs more than 5,000 staff to serve over 25,000 students in 265 public schools in 22 school districts in St. Louis County. The Special School District has held spending growth to under one percent for the past three years; however, to do so it had to cut staff by five percent and non-personnel expenses by 19 percent. Given the cost related to attracting and retaining highly skilled educators (many with advanced degrees) for those with special needs, this levy plays an important role for the Special School District of St. Louis County in the coming years, permitting it to grow to help more students, as well as address necessary capital improvements.

### New Missouri Law Brings Changes to Special Education Due Process Hearings

Parents of children with special needs in Missouri who feel their children are not receiving proper instruction won a victory in 2012. On July 5, 2012, Governor Jay Nixon signed Senate Bill 595 into law. Effective August 28, 2012, special education due process hearings moved from the Missouri Department of Elementary and Secondary Education (MODESE) to the Missouri Administrative Hearing Commission (AHC).

Under the old system, mediation was the first step. A three-member panel from MODESE then heard complaints from parents regarding their children's special education in cases where mediation did not resolve the issue or did not take place. Special needs advocates argued that despite free mediators being available to school districts to hear these complaints, many districts would jump to MODESE instead, because the panel often sided with the school district (panel members were often retired special education directors). By moving the hearings out of MODESE, the legislature hopes to drive more cases to mediation and provide an unbiased system for those cases which cannot be resolved through mediation.

The AHC commissioners will be specially trained to hear special education cases and required to show at least five years of employment independence from both school districts and families of individuals with special needs.

Additionally, the legislation provides an expedited process for parents challenging a disciplinary change of placement or placement of a dangerous or violent student. This legislation will bring Missouri law up to date with other states which have already adopted similar due process protocols.

#### *Travel, cont'd from page 2*

travel to any person they believe would endanger the health and safety of the other passengers. This can apply to someone they deem unable to assist themselves. Airline personnel cannot ask what disability a traveler has. However, they may ask questions to understand what the traveler can and cannot do and what accommodations the airline must make for the traveler.

When passengers are refused boarding, they must be informed by the airline how their presence on the flight would endanger other passengers. However, the airline does not have to provide the reasons for refusing boarding at the time of refusal but can wait until after the date of travel.

The best way to avoid unexpected delays is to be prepared. Knowing the rights of travelers with disabilities, how to enforce those rights, and the questions airline and airport personnel are allowed to ask are all key to ensuring a successful trip.

This overview by no means addresses every nuance of the Air Carrier Access Act and travel by air for persons with disabilities. There may be special rules that apply to particular situations, so be sure to research this before travel.

#### *Documents, cont'd from page 1*

4. Guardianship papers for an adult with special needs, as well as a list of advocacy organizations which may help a future guardian answer questions that arise.
5. A care plan regarding the preferences and tendencies of the child with disabilities that the parent or guardian would want future caregivers to know. This document, while non-binding, should be updated annually to ensure the child's needs, preferences, and habits are fully accounted for by a caregiver who does not know the child as well as the parent or guardian does.
6. A list of government benefits the child may receive, names of government agencies or case workers that have dealt with the case, and copies of any applications filed with those agencies. This can make the task of re-application easier for a guardian who may have never seen these forms, and ensure the child receives the benefits he/she is entitled to.
7. Finally, any tax returns filed for the child with special needs and information about housing, school, or work.

Gathering these documents together now will benefit future caregivers and provide better organization today as well.

# Spotlight: LoveU2Pieces

LoveU2Pieces is a St. Louis-based nonprofit "dedicated to raising funds necessary to provide education, support and opportunities for families living with Autism Spectrum Disorder (ASD)." LoveU2Pieces events include trivia nights, golf scrambles, art exhibits, and concerts.



Families dealing with the unique stresses of ASD often lack the necessary resources to meet their needs. They may also lack the resources or opportunities for respite care. LoveU2Pieces funding helps provide financial support for these families, including more opportunities for respite care.

In addition to its fundraising efforts, LoveU2Pieces provides Community Outreach Programs that help connect families living with ASD, as well as raise community awareness regarding issues that surround living with ASD. Topics have included: "The View from Here," presented by artist and autism self-advocate Taylor Crowe; "Sensory Sense: Bridging the Gap Between School and Home," presented by Cindy McFarland, occupational therapist; and "Promoting and Supporting Social Interactions," presented by Natasha Bailey, ABA therapist and consultant.

For more information, please contact Leigh Rolnicki, Director, at 314.952.5072 or email [Leigh@loveu2pieces.org](mailto:Leigh@loveu2pieces.org). Visit their website at [www.loveu2pieces.org](http://www.loveu2pieces.org).



DANNA MCKITRICK, P.C.  
ATTORNEYS AT LAW

7701 Forsyth Blvd., Ste. 800  
St. Louis, MO 63105

## Misty A. Watson

314.889.7155 (p)

314.725.6592 (f)

[mwatson@dmfirm.com](mailto:mwatson@dmfirm.com)

[@mistywatsonesq](https://twitter.com/mistywatsonesq)



*Misty focuses her practice on estate planning and administration, including probate. She counsels individuals, families, and business owners in the creation of trusts, wills, financial and health care powers of attorney, guardianships, and conservatorships.*



# Making Musical Theater Accessible



Does your child with special needs love to sing, dance or act? If you are looking for opportunities for your child to explore musical theater, dance and/or acting, Stages St. Louis offers its Access the Arts and Troupe Broadway programs. Stages St. Louis is a non-profit organization committed to musical theater education and performance.

Access the Arts include classes, workshops, and performance opportunities for children with special needs. Classes are weekly year round as well as during summer daycamp.

Troupe Broadway is a performance ensemble comprised of teens and young adults with special needs. The ensemble develops and rehearses a revue and performs in the St. Louis area and beyond.

In addition to these programs, students may participate in any Stages' Academy class or workshop in an inclusive environment. For more information on Access the Arts, Troupe Broadway, or other Academy inclusive or specialized class opportunities, call 636.530.5959 or visit the website at <http://www.stagesstlouis.org/Education-and-Outreach/Access-the-Arts/>.

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