

# PARTNERS IN POLICYMAKING

2012 winter

inspire action & vision

## Regarding GUARDIANSHIP



A court-appointed general guardian oversees the person and/or all of their property and assets. A limited guardian is authorized by the court to exercise specific and limited control over the person, their property and assets.

A guardian of an incapacitated person is appointed by the court to assure the essential requirements for the health and safety of the ward are met and/or manage their financial resources.

A guardian *ad litem* (GAL) is appointed by the court to assist in the selection

process of a guardian. Once the court proceeding is complete, the GAL's job is over.

*All persons alleged to be incapacitated or partially incapacitated have rights which include being in attendance at their hearing; calling for witnesses and cross-examining them; presenting evidence; submitting appeals; court-appointed representation and requesting their hearing to be closed to the public.*

Guardianship is the result of legal proceedings and should be "the option of last resort. Every major disabilities advocacy group has adopted this philosophy as have we at the Oklahoma Department of Human Services Developmental Disabilities Services Division."

-DHS, 2005 & Interface, 2007

## CAAVA

Court Appointed  
Advocates for  
Vulnerable Adults  
of Oklahoma  
[caava.org](http://caava.org)

## Also...

### Letter of Intent.

- Outlines long-term needs and wishes of person with perspective from family
- Provides relevant medical and financial information
- Provides access to records

## SPECIAL NEEDS TRUSTS: Protecting Assets & Benefits

**Breaking News.** You are going to die. And when you do, your loved ones should feel they still have financial security.

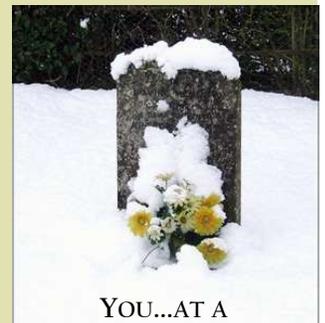
Money in a special-needs trust (also known as supplemental needs trust) can be used for expenses before or after a caretaker's death and are not counted toward the \$2,000 asset limit set by Medicaid and Social Security. Anyone can deposit funds into this sort of trust and not jeopardize government benefits.

Before investing life insurance and retirement benefits into a family member's special needs trust, consult with a tax attorney.

A well-structured trust relieves government aid recipients, their parents and siblings of several "what if" questions.

A special needs fund often has both a guardian and a trustee. If a family member needs assistance making financial decisions, the guardian partners with them articulating the person's needs and desires. Management of the trust falls to the trustee and people with professional accountancy and financial management experience should be selected.

Adapted from "Making Sure the Kids Are All Right" by Veronica Dagher, *Apostrophe*, Summer 2011.



YOU...AT A  
FUTURE DATE.



Five 4 Google

Smarter SMART Phones



All too often, our kids impress us with their technology skills. Now parents are finding SMART phone and tablet apps that encourage children's

learning, keep them organized and assist with expression. Here are some of the most well-reviewed:

Animal Writing HD: interactive writing, listening and reading skills using zoo animal sounds.

ArtikPix: assists children with speech articulation challenges and popular with speech pathologists.

Turn Taker: provides audio or visual cues for children learning how to share and not inter-

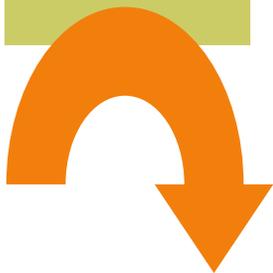
rupt one another.

Discover My Voice: a simplified augmentative communication device.

Experimenter: illustrates more than a dozen science experiments that kids will find beyond cool! Step-by-step directions, video and safety rules included.

Pocket Picture Planner: helps with schedule development by using pictures instead of words.

Balloonimals: lets kids build a zoo's worth of animals in a magi-



SNApps4kids.com

"wheelchair clamp mount"

ChristopherReeve.org

ATMac.org (for Mac users)

EpilepsyU.org

Apps for Self & Family Advocates

Seizure Log: tracks seizure activity and characteristics across time.

RemindMe Prescription Device: provides reminders and tracking for those who take daily prescribed medicines.

ClearRecord Premium: is a recording device that suppresses background noise as well as an adjustable playback speed for listeners.

LocateMeNow: identifies

your exact location (street address, city and zip) with the push of a button.

Fluid Tunes: allows music lovers to peruse their downloads with the use of just a camera and their hands, head or feet.

Citirollers: gives wheelchair users an idea of accessible areas, facilities and public transportation in some of our largest US cities.

QuickADA provides quick reference to the codes, measurements and design plan standards for the Americans with Disabilities Act.



IEP Checklist: provides the legal requirements, definitions and note taking sections for your child's IEP.

PARTNERS ~ Time to Apply

Do you know someone who would make a great advocate? Partners in Policymaking applications are due May 20, 2012. We will gladly mail brochures, applications and the parents' testimonial letter and often make presentations about PiP. We rely heavily on alumni to recruit new students!

GET IN TOUCH!

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## TEFRA

### Tax Equity and Fiscal Responsibility Act of 1982

Many parents raising children with medical and other unique needs wonder if they are eligible for TEFRA.

TEFRA allows the state to make Medicaid options available to children with intellectual or physical disabilities that did not qualify for Social Security Income (SSI) because of the family's income. TEFRA covers expenses for children who are eligible for full-time institutional services and/or have extraordinary medical expenses to be cared for in their home.

If a family already has insurance and becomes TEFRA eligible, TEFRA pays for eligible expenses after insurance pays. TEFRA recipients are given a SoonerCare card as proof of coverage and TEFRA fam-

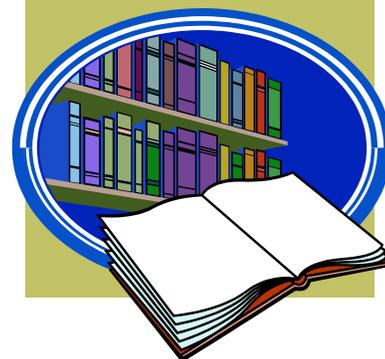
ilies must be recertified for eligibility annually. TEFRA applications take several months to complete and approve and begin with a denial letter for SSI from Social Security. A DHS case worker at the local office will manage TEFRA applications but TEFRA is managed by the Oklahoma Health Care Authority.

In 2011,  
approximately **400** Oklahoman  
children received TEFRA benefits.

[www.ohca.org/research/data](http://www.ohca.org/research/data)

Check out the Arc's new  
Medicaid Reference Desk  
for self-advocates and  
families @

[WWW.THEDESK.INFO](http://WWW.THEDESK.INFO)



## Play WORDS WITH PARTNERS

**BLOCK GRANT:** Federal funds that a state or local government may use, at their discretion, for programs (such as Title V which assists childbearing women and their families).

**IDIOPATHIC:** A disease or condition of unknown origin. For example, idiopathic seizures are those that occur due to unknown causes.

**INTRINSIC MOTIVATION:** When a person chooses a behavior or activity because they receive a personal reward versus being motivated by external forces such as salary, treats, praise or absence of punishment.

**PER CAPITA CAP:** A ceiling placed on Medicaid expenditures *per beneficiary* but does *not* limit the number of beneficiaries covered by the program.

**PRESIDENT PRO TEM:** The senator who presides over the US Senate in the absence of the Vice President. At the state level, the Pro Tem is the senator who presides over the Oklahoma State Senate in the absence of the Lieutenant Governor.

**QOL:** Quality of Life, a measurement used in medical and sociological fields to establish how happy and secure people and communities are.

**TRISOMY:** the presence of three copies of a chromosome in a cell versus the typical two. Trisomy 21 is one example of this genetic condition and is also called Down Syndrome.

**WHITE HAT ISSUE:** An issue that no legislator wants to oppose because it appeals to so many constituents. Therefore, any opposition often comes in the form of how much the proposal would cost.

OKLAHOMA DEVELOPMENTAL DISABILITIES COUNCIL

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Final Thoughts

*How we treat  
people lives in  
the language we  
choose*

—Speech/Language Therapist

ADVOCACY MATTERS

*If you are not at the table  
in Washington D.C.,  
then you are on the menu.*

*- Lobbyist adage*

And the Award  
Goes to...



Sometimes, advocates come across a message that makes us realize *we have a lot of work left to do*. See above for a bizarre, insensitive example.

While this message urges us to love those with disabilities, our message in response is *get over yourself*.

We proudly announce our “winner” for the *least People First, highly obnoxious message*. Let’s make sure we deliver person-centered, respectful messages!

It is commonly believed that people with brain injury have only one year to make measurable recovery.

Also known as the “window of opportunity,” do you know who came up with this brain injury prognosis?

ANSWER:  
Insurance companies

Did You Know?

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