

ARCCORPS *Newsletter*

NEWS FOR VOLUNTEER GUARDIANS AND ADVOCATES

SPRING 2006

ARCCORPS VOLUNTEERS FIND TIME TO DO MORE

Ron and Karen Wasson of Noble, Okla., are remarkable. Really remarkable.

They have adopted a 7-year-old daughter with special needs. They are foster parents for a 14-year-old boy who also has special needs. Ron and Karen are both ordained ministers. They manage a 5.5-acre farm where they raise dairy goats, make cheese, and sell eggs. Ron is an advocate through the ARCCorps program for a man with cerebral palsy who lives in a supported living setting. And last but not least, Karen is approved to become a limited guardian through ARCCorps for a woman with developmental disabilities.

Ron's advocacy on behalf of the young man he serves, who in this story is called "T", has included urging him to be more assertive, being proactive in respect to his Individualized Plan (particularly in respect to T's continuing education), and helping him make good decisions.

Karen says that Ron and T

have been friends so long that Ron is able to redirect him in cases when issues get bogged down or when T gets entrenched in an issue.

"Ron can say 'chill' and T listens to him," Karen says.

As for her, some of Karen's friends have called her crazy; others say that she and Ron are always

"fighting." When it comes to advocacy, the Wassons see it another way.

"We don't look at it as fighting when it comes to the life of another human being," she says.

Karen's passion for serving individuals with disabilities is borne of her experience caring for a daughter with special needs.

Her daughter was born in 1974 with spina bifida and, upon reaching school age, was labeled "uneducable" by the Wisconsin school district in which they

lived. At that moment, Karen became an advocate for life.



"THERE'S ALWAYS TIME FOR MORE. WE ARE SUPPOSED TO HELP OUR FELLOW MAN... AND YOU CAN DO IT!"

— KAREN WASSON

"I don't take 'No' for an answer when it comes to our kids. We all need to be treated with respect and dignity," she says. Her attitude was

and remains: "How dare you tell me my child doesn't belong."

"Because of my daughter, I

don't hold back like I did. I was a very shy, introverted person. You can't stand back and expect someone to do what you know you should do. As St. Francis of Assisi said, 'Preach the gospel often and, when necessary, use words,'" she says.

Whether it is with words or sign language, ARCCorps advocates **Bob and Cathy Polony** of Oklahoma City are determined to create a communication bond with three men with developmental disabilities

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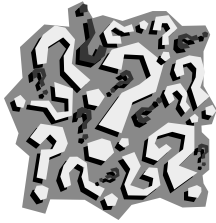
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WHAT VOLUNTEERS WANT TO KNOW

ANSWERS TO A FREQUENTLY ASKED QUESTION

by Aaron Brown,
Assistant Executive Director of TARC
and ARCCorps Program Coordinator



FAQ

Question:

What can a guardian do if the service recipient has a reduction or denial of service, which the guardian does not agree with?

Answer:

It is a requirement that you, as the guardian, receive notice of any changes in services, whether they are reduced, increased or denied. This notice should come to you from the Oklahoma Department of Human Services/Developmental Disabilities Services Division (DDSD) case manager in the form of a "Notice of Action" (also known as a DDS4 Form). The notice should specify the dates when the service will change and the period during which an appeal can be requested. Guardians should always review changes in service to make sure they agree with the decision, because often it can have a big impact on the service recipient.

In most instances, changes in services are discussed prior to their taking place. For example, team meetings or IP meetings include team discussions on change in services. Although you may not have agreed with the change discussed in the meeting, that may not mean the change will not be made.

Case managers and plan of care reviewers must always look for ways to reduce needless services. The Notice of Action should have instructions on how and to whom to appeal the change in service. If you have specific questions, you should contact the case manager (or his or her supervisor) to discuss the procedure for appeal.

Once you have requested an appeal, that service is "frozen." It cannot be changed until it goes before an appeals officer to decide the next course of action, which would be to maintain the service or deny the appeal. You may request documentation from other team members and service providers to assist you in making a case for not reducing the service.

If a service is changed without your notice, you should contact the case manager immediately to determine why you did not receive a Notice of Action. Usually in such a case, the service is reinstated until you receive notice of the change. If that does not happen, you should contact the case manager supervisor, or the area manager.

Every situation is unique. There are no guarantees that you will be granted or win an appeal. Reducing unnecessary services is not a bad thing. It helps other individuals with developmental disabilities who are on a waiting list and

not receiving any services.

However, if you feel strongly enough that a service reduction, in whatever area of the person's life, is going to have a negative impact, you should consider requesting an appeal. After all, you are there to advocate for what you think is best for the person for whom you are the guardian.



STAY CURRENT!

THE TARC ONLINE

CALENDAR LISTS

DISABILITY-RELATED

EVENTS AROUND THE

STATE AT

WWW.DDADVOCACY.NET



*NOMINATION FORMS
ARE NOW AVAILABLE
FOR
TARC'S*

*2006
Advocacy
Awards*

*VISIT
WWW.DDADVOCACY.NET
AND CLICK ON
"WHAT'S NEW" TO
DOWNLOAD A
REGISTRATION FORM.*

WELCOME NEW ARCCORPS VOLUNTEERS

TARC welcomes the following ARCCorps volunteers who were matched as advocates or guardians in the 1st Quarter of 2006. *Thanks one and all!*

Matched (1Q2006):	Sharilyn Edlund	Mary Padilla
Sandra Bell	Tammy Foreman	Judy Phillips
Frances Clure-Harrison	Melani Lazatin	Mary Tidball
Hardy Comstock	James Logsdon	Richard Ward
Sherri Cooper	Vontreba Maddux	Karen Wasson
Sidney Donovan	Ruth Oliphant	Doris Watkins
Rose Dunford	Terry Oliphant	James Wilson



WELCOME!
TARC WELCOMES

**AMIE
FARINELLA**
AS OUR NEW
SELF-ADVOCACY
COORDINATOR.

IF YOU ARE THE
GUARDIAN OR
ADVOCATE OF AN
INDIVIDUAL WHO LIVES
IN NORTHEASTERN
OKLAHOMA AND
WHO MIGHT BE
INTERESTED IN
PARTICIPATING IN
TULSA PEOPLE FIRST
OR OTHER
**SELF-ADVOCACY
ACTIVITIES**, CONTACT
AMIE AT 918-582-8272
OR 800-688-8272

WEB RESOURCES FOR GUARDIANS AND ADVOCATES

Adaptive Clothing

The disAbility Resources website features a list of merchants that provide adaptive clothing, footwear, outerwear, and personal temperature control devices. Visit <http://www.makoa.org/clothing.htm>

Assistive Technology

The links page at the Oklahoma AbleTech website lists hundreds of resources on subjects as far ranging as home modification and assistive technology vendors to travel and sports tips for persons with disabilities. View the list at <http://okabletech.okstate.edu/res/links.html>

Health

The American Association on Mental Retardation (AAMR) provides a lengthy list of health-related resource links, covering topics such as aging, emergencies, future planning, health, and transitions. Visit http://www.aamr.org/Groups/committees/health_links.shtml

Independence

The "Access to Independence" section of the National Organization on Disability (NOD) website features technology news and information about access to housing, health care, transportation, and education. Visit <http://www.nod.org/index.cfm?fuseaction=Page.viewPage&pageId=17>

Medicare Part D Prescription Drug Coverage

A website developed by the Disability Policy Collaboration, a partnership between The Arc of the U.S. and UCP, is designed to help individuals who receive Medicaid and Medicare benefits (dual eligibles), their families and caregivers, and advocates for people with disabilities nationwide understand the new Medicare prescription drug coverage, called Part D. Visit <http://thedesk.info/PartD/>

Personal Stories & Helpful Tips

The Beach Center on Disability at the University of Kansas has compiled a list of "real-life" tips, suggestions and recommendations from its website users on a variety of topics including quality of life, health care, and positive behavior support. Story topics are also sorted by disability type. Visit <http://www.beachcenter.org/stories/>

TARC Newsletter

The TARC Newsletter is Oklahoma's leading information source on issue impacting the lives of people with developmental disabilities and their families. The most current edition of the TARC Newsletter is posted online at the "What's New" section of the TARC website at www.ddadvocacy.net

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ADVOCATES.

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ARCCORPS VOLUNTEERS... (CONTINUED FROM PAGE 1)

for whom they advocate. The three are housemates and have varying degrees of communication skills. Bob is looking into taking night courses in American Sign Language to enhance his ability to strengthen his relationships with the men.

Bob and Cathy are fairly new ARCCorps advocates, but they are making the most out of the opportunities they have to learn about the three men and understand more about their lives. "It is important for us to attend any meetings or discussions about them. Plus, we've recently opened up our home pool and are seeing how we can bring them to our home on a regular basis," he says.

The Polonys are looking forward to getting to know all three men — individually and as a group. "We want to look at holidays with them and find ways to just peek in on them from time to time," Bob says.

Both Bob and Cathy know that it is not just the holidays but the little things that count. Having learned that one of the men likes the harmonica, Cathy found one and plans to take it by on her next visit.



"WE WANT TO LOOK AT HOLIDAYS WITH THEM AND FIND WAYS TO JUST PEEK IN ON THEM FROM TIME TO TIME."

— **BOB POLONY**

that convinced Bob and Cathy to join ARCCorps. "We're so glad we did," says Bob.

If you know someone who might be interested in becoming an ARCCorps advocate or guardian, contact your recruiter/coordinator.

CATCH ARCCORPS IN ACTION

Visit with ARCCorps representatives at the following events:

June 2, 9 am to Noon
— *"Stand for Children"*
Day at Cherokee
Courthouse Square in
downtown Tahlequah.

June 9, 8:30 am to 3 pm
— *"On the Road" Family*
Perspective Conference
at the Best Western in
Sallisaw. Sponsored by
OASIS, FEAT, and DDSD.