

Dear Friends of ACT,

My eyes were opened last week to an issue I'd never considered before: the potential harms of guardianship.

Here's what I didn't know:

Guardianship is almost always plenary or total (But it doesn't need to be.) The number of adults in guardianship today has tripled from 500,000 in 1995. Studies show that people who exercise little or no self-determination are injured by this prohibition, developmentally, physically, and psychologically. People who determine for themselves what their lives will be like are healthier, more independent and well-adjusted, and better able to recognize and resist abuse. These revelations came at a presentation I attended last week by attorney Jonathan Martinis on Supported Decision-Making (SDM).

Martinis says SDM is an alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the "need" for a guardian.

He's calling for the use of SDM as an alternative to guardianship, which needlessly strips people with disabilities of their rights. It's a paradigm, he says, not a process. It can and should change.

You can find more information about SDM at: www.supporteddecisionmaking.org.

We try to do what we say here when it comes to choice. We do person-centered planning with every individual who receives services at ACT. We ask each person what she or he prefers, wants, and aspires to. But in all my years in this field, I've never heard the phrase "supported decision-making"

The idea rests on an understanding that everyone needs supports. I don't make decisions about retirement plans without the support of my financial adviser. I get a diagnosis and advice from my doctor before medical treatment. I talk to my mechanic and get her advice on repairs to my car.

We ALL need supports. Although it may not seem like it, none of us makes it in life alone. The supports that a particular person with a disability receives may simply be different from the ones you receive.

Your life should not be dictated and controlled by a guardian simply because you need support.

Instead, people with disabilities can direct their own lives and regain access to their rights through SDM.

This idea is beautifully illustrated by the story of 29-year old Jenny Hatch, a Virginia woman with

Down syndrome. https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html

Jenny knew by direct experience what I just came to know, what Rep. Claude Pepper, Chairman of the House Select Committee on Aging said in his prepared remarks at a Briefing on Abuses in Guardianship (Sept. 25, 1987): "The typical ward has fewer rights than the typical convicted felon. They can no longer receive money or pay their bills. They cannot marry or divorce. By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty."

Let that sink in.

Because we are helpers in a helping profession, and because we've seen the effects of isolation, abuse, and neglect on people with disabilities, we're inclined toward being protective.

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Mark Hassemer
Executive Director

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What I've come to see, what's causing me to genuinely reconsider how we serve those in our care, is the harm of being over-protective.

There is dignity in risk. Taking a chance and pursuing what you desire elevates everyone. Even if we choose poorly. Even if we fail.

It could be that convenience is driving the rapid escalation of guardianship. It's messier, more complicated, and time-consuming to ask a person what he or she wants and then do it. He might get injured on the job. She might seek a relationship with someone we don't like. She might spend a portion of her income on a "frivolous" hobby. He might buy a six-pack of beer.

In some circumstances, Martinis says guardianship may be needed. For instance, guardianship could be appropriate in emergency situations when someone is incapacitated and cannot give consent; or to support people who face critical decisions and have no ability to make them or interest in doing so, or need immediate protection from exploitation or abuse.

If you're not completely sold on this notion of SDM, before considering guardianship, at least ask, "What else can we try?"

Life, liberty, and the pursuit of happiness are the inalienable rights of all human persons, says

the Declaration of Independence. These rights should not be snatched away reflexively simply for the convenience of care-givers or the fear that something bad might happen if one chooses poorly.

That's what happened to Jenny Hatch. After she was hit by a car while riding her bike, her guardians sent her to live in a group home. She hated it. She wanted to go back and live with her two friends. Her friends helped her hire a lawyer and fight the guardianship petition. They sat down with her and explained her legal situation. They helped her understand her choices. And then they listened and understood when she expressed for herself what she wanted.

Although the Court found she needed a guardian, the need is temporary. And the Court considered Jenny's preferences. Her friends became her guardians.

Martinis called that decision "the rock that starts the avalanche."

I started feeling the rumble of that avalanche last week. And I'm thinking about what we can do at ACT to implement SDM and restore access to the right of self-determination inherent in everyone we serve.

Until next month,

Mark



Dawn's New Home in ISL KEEPS HER CLOSE TO HER MOM

Within the first week of moving in to town, Dawn visited her mom in Moberly for the first time in three years!

"This was huge for Dawn. She was very excited to have that opportunity," Community Living (CL) Supervisor Hannah Prince says.

Dawn, who was living in Kansas City, first visited ACT's Individualized Supported Living (ISL) in May. She then chose Columbia to be closer to her family and guardian.

"She loved the house and Abby [who also lives in the house] from the start. It helps that Abby and I made cookies before she got here!" Prince jokes.

It is no wonder Dawn gets along with Abby so well. They have very similar interests.

"I like jewelry, dressing up, shopping, going to the mall, swimming, and watching TV. So does Abby," Dawn says.

"They became fast friends!" Prince observed.

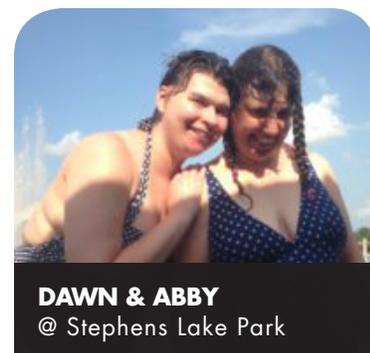
It's been a month since she moved in. She has settled in nicely. Her room is decorated and the new roommates have already settled into a routine.

"Dawn typically joins Abby watching Wheel of Fortune and cheering for a specific contestant," Prince says.

They've been busy, too, having some summer fun.

"We have been to Stephens Lake Park, the swimming pool, the mall, and the State Fair!" Dawn says.

Welcome to ACT, and Columbia, Dawn! We are thrilled you are here. •



September 11-17 2016

DSP WEEK

DIRECT SUPPORT PROFESSIONAL WEEK

The week of September 11-17, 2016, has been declared National Direct Support Professionals (DSP) Week to recognize the work of community providers who provide supports to our friends, family and neighbors with intellectual, developmental, physical, and other disabilities.

Much of the work completed by Columbia's Direct Support Professionals (DSPs) goes unseen, but that does not make it any less critical to this community and the individuals whose lives are enriched daily by these incredible men and women.

"It is difficult to be a DSP...there are times that they don't receive direct appreciation while they are caring for our individuals," says Craig Valone, Director of ACT's Day Program. "Our DSPs are natural caregivers and do a service that couldn't go without being done."

ACT will be showing gratitude to our DSPs all week long! Each day is earmarked with something special as a way to say thank you. DSPs among the different programs will be showered with food, prizes, adoration and more!

"Each day I will deliver goodies with a note of appreciation to the DSPs in my program. I greatly appreciate their hard work... everyday they have a positive impact on the lives of the individuals we

serve. It is nice to remind them of that," says Jessica Mahon, Director of ACT's Career Services. To kick off the week, ACT and other partnering agencies (Boone County Family Resources, and Woodhaven) are hosting a reception to honor our DSPs from 1pm-3pm on September 13 at Woodhaven.

A proclamation will be read declaring the week of September 11-17 as Columbia's own DSP Week.

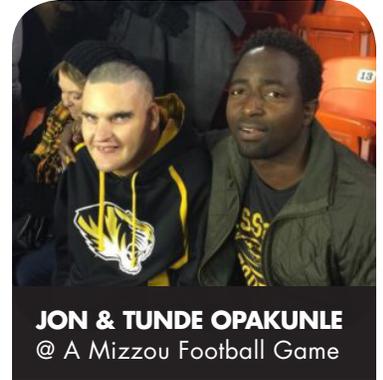
All are invited to join the event, which will also feature a ribbon cutting by the Columbia Chamber of Commerce, heartfelt remarks from DSPs, and light refreshments.

The need for quality supports provided by DSPs is constantly growing as the residents of this community age and the number of people living with disabilities continues to increase.

Columbia and Boone County are blessed to have so many dedicated men and women who have chosen the Direct Support profession. Their work empowers so many individuals with developmental disabilities to live independently as members of this community.

Day Program's Manager Michelle Bell says, "Without [DSPs] we would not be able to provide the service we do. They are crucial to our mission and the backbone of our program."

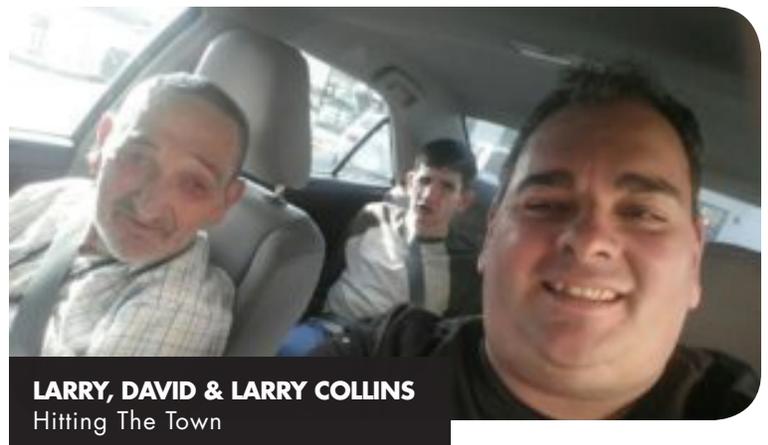
During Direct Support Professional Week, ACT, Boone County Family Resources, and Woodhaven would like to encourage the public to learn about the services provided by DSPs and to help us celebrate the great works of these men and women. •



JON & TUNDE OPAKUNLE
@ A Mizzou Football Game



PHOEBE GRAY & BUDDY
Dancing



LARRY, DAVID & LARRY COLLINS
Hitting The Town

MARIAH

Is Growing Professionally in her Position at Children's Place

In April, a former ACT Career Services (ACS) Career Specialist approached Children's Place in the Columbia Mall about diversifying their workforce.

Mariah was hired at the children's clothing store the next month. She's doing a great job.

Since then, a new store manager, Shannon Bowman, has come on board. He is thrilled with the relationship developed with ACS.

"Mariah is fantastic about completing other duties as assigned. And she never has to be asked twice, even if it's something she's never done," Bowman says.

As Retail Sales Associate, Mariah folds and hangs clothes, greets customers, operates the cash register, and assists customers.

Mariah, a quiet person, struggled at first with customer service. She used every interaction with customers and coworkers as a chance to improve her interpersonal skills.

As any great supervisor would do, Bowman uses Mariah's strengths to make store operations the best they can be.

"Shannon gives Mariah opportunities to use her skills," ACS Supervisor Suzan Schuetz says. "Mariah is

organized and methodical, traits that enable her to excel at product and sign placement, as well as product straightening, sorting, and facing."

Bowman has been Mariah's biggest supporter, providing guidance, instruction, and honesty about expectations. He has shown dedication and patience while introducing new skills, giving her time and opportunity for plenty of practice.

When Mariah requested more hours, he worked hard to fulfill her request while working intensively with her on the specifics of certain tasks.

As Mariah has grown more confident in her position, Bowman and other store associates have been working collaboratively with ACS to formulate and implement a plan for the gradual reduction of services ACS provides.

"Because of the clear and consistent communication with Bowman and other associates, it truly feels as if we are on the same page providing supports to Mariah," Schuetz says.

"It is great to have a connection with The Children's Place. We are looking forward to continuing and building on this collaboration." •



SHANNON BOWMAN
Store Manager

UPCOMING EVENTS

September 5

ACT facility based offices closed for Labor Day

September 11-17

Direct Support Professional Recognition Week

September 13

DSP Week Reception
1403 Hatham Place
1pm-3pm

September 23

Tigers on the Prowl Fall Gala

October

National Disability Employment Awareness Month

OCTOBER IS
**NATIONAL
DISABILITY
EMPLOYMENT
AWARENESS MONTH**

The 2016 National Disability Employment Awareness Month (NDEAM) theme is “#InclusionWorks

Observed each October, NDEAM celebrates the contributions of workers with disabilities and educates about the value of a diverse workforce inclusive of their skills and talents.

Download this year’s poster to show your support of workplace diversity at the United States Department of Labor, Office of Disability Employment Policy website.

SHOP & DONATE

You can now donate to ACT by shopping at Gerbes, Schnucks, and AmazonSmile andJustGive.org!

At Gerbes and Schnucks, simply apply for their community/ rewards program, pick ACT as your designated charity, and shop away!

When shopping at AmazonSmile, create an account, pick ACT as your charity, and again, shop away! JustGive makes donating to charitable organizations easy. Go to their website and search Alternative Community Training to donate. You can even pick to give one time, monthly, or to put on a registry.

CoMoGives
**FUNDS
GIVE**
 CoMoGives.com

To everyone that participated in CoMoGives, THANK YOU!!

100% of the money raised in this campaign goes to the individuals ACT serves.

In 2016, a family can now afford to buy a new kitchen appliance; Robbie could pay for crucial dental

work; Abraham and his family got a family pass to Columbia Parks & Rec pools; and more!

Also in this newsletter, read about Jayden - a six-year-old boy recently diagnosed with an inoperable brain cancer. Jayden’s family of four is struggling but CoMoGives funding afforded them some relief...a brand new washer and dryer!

Now Jayden’s single mom, Karla, can take care of laundry at home instead of hauling the whole family to the laundry mat.

Keep in touch for more heart warming stories like these brought to you by the CoMoGives.

THANK YOU FOR SUPPORTING ACT!

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