Alternative Community Training

Dear Friends of ACT,

In my November 2015 letter to you, I wrote with great emotion. I vented my frustrations about the injustices I felt were perpetrated by our State authorities. I think you’ll agree that someone must own this problem.

I talked about rebasing. I want to address it in this letter, too. This time, I’ll do it calmly, but with no less passion. (One reader called that last letter a “zinger.”)

Rebase was a word that was new to me just a few years ago. According to the Oxford English Dictionary, it is a verb that means to establish a new base level for a tax, a price index, or, in this case, a compensation percentage. At this point, to me, it simply means equality, a level playing field. It’s what we want. The people we serve deserve it.

Rebasing will adjust the oldest and lowest contract provider rates in an effort to move steadily toward a standard rate for providing a given service, regardless of who provides it.

If you didn’t read my previous letter on this topic, you probably won’t know that new entrants accessing the system for Individualized Supported Living services are receiving much higher rates for services when compared to those who’ve been receiving services for a longer period of time.

Rebasing, according to the 2009 Department of Mental Health (DMH) Report to a Senate Select Committee, should occur until rates have been increased to the current actual cost of providing services.

The plan was for this problem to be solved in about five years, subject to appropriations or redistribution of DMH funds. That was easily said, but not easily done, it turns out.

In 2013, as the result of legislative action, rebasing began. It brought some of the oldest rates to about 60% of the current rate for providing services to new entrants.

In 2014, the legislature approved rebasing funds; but the Governor vetoed the funding.

In 2015, the legislature again approved rebasing funds; but the Governor withheld them, based on concerns about balancing the budget.

In December, we met with a Senate Policy Analyst in Sen. Kurt Schaefer’s office in the Capitol. Joining me were ACT Board members and the parents of a young lady we support in an Individualized Supported Living home. We stated our case for rebasing.

From early indications, we were heard. Following the meeting, the Senate asked the Division of Developmental Disabilities for alternative rebasing options.

Now, in 2016, the Governor proposed rebasing funds in his budget recommendation to the legislature. Early in the legislative session, which ends May 13th, a House Appropriations Committee added rebasing dollars to the Budget (HB 2010).

Next, we took our message to local legislators. We met with Rep. Stephen Weber and Rep. Caleb Rowden.

Steve Lee provided testimony to the Senate Appropriations Committee Hearing in late January. He talked about the need for rebasing.

Steve is the parent who, with his wife Suzy, has been attending meetings with our legislators. They are champions for this cause and the cause of people with disabilities.

Many people representing organizations and associations provided testimony that day. Lobbyists gave their input, too.

Steve, unlike others, spoke as a parent. Although his testimony may not have seemed as scripted as some, he offered a perspective that was different and more impactful than the rest. He talked about his daughter, Abby.


In This Issue

Day Program Offers Lots of Fun Favorites

Lawrence Lile, an Affordable Accessible Housing Champion

Eli Excels in his Job at Mizzou Athletics Training Complex

March 2016 Tip from Tara: Let’s all make some new paths!

Mark Hassemer
Executive Director

DEAR FRIENDS OF ACT
Continued on page 2
You can be certain that partisanship is alive and well in Missouri. That’s become absolutely clear to me. Legislators may be quick to point fingers at the Executive Branch, or at one another, for our failure to accomplish true rebasing. But we can and should get past this.

This should be and can be a time when everyone does the right thing, rising above partisanship and political posturing to support and actually accomplish rebasing. While we’re at it, please, let’s address the oldest and lowest rates first.

I don’t care who gets credit for solving this. A little placard, given to me by my late father-in-law, sits on the credenza behind my desk. It reads: There is no limit to what a man can do or where he can go if he doesn’t mind who gets the credit.

If you’re a parent or family member of a person served by a provider like ACT, please call your legislator and ask him or her to support rebasing in HB 2010. Please don’t back down on this message until we have equitable rates across the state.

I’ll stop now. I’m starting to get worked up again!

Until next month,
Mark
After seeing his father-in-law move into an Independent Supported Living (ISL) home in Arizona in the early 2000’s, Lawrence Lile, an engineer, decided he wanted to be a part of the solution here in Columbia.

“My father-in-law had a great set-up at his new house. It suited all of his physical needs and the relationship between landlord and tenant was long-term. I wanted to help provide that for people with disabilities here.”

The lack of affordable housing in Columbia is a serious challenge. As a result, ACT staff struggle to find high quality homes in the community for individuals with almost no budget flexibility.

During a two-day affordable housing summit in Columbia last December, Randy Cole, the City’s Housing Programs Supervisor, said the City’s gross median rent has increased over the past five years.

ACT’s Community Living (CL) program offers services ISL homes to people with disabilities.

Many factors stack the deck against the CL program’s work to assist individuals with finding homes.

College students drive up the cost of housing in Columbia. Because the stream of incoming students seems to never end, the typical landlord is unlikely to negotiate a lower price.

And most homes available for rent just are not accessible to people who need particular types of support.

Individuals supported in CL simply cannot afford renovations. Most landlords won’t pick up the bill.

In a reality where most tenants come and go within a year, it can be difficult to see the long term benefits of changing a home for tenants. This is especially true when there are so many prospective tenants who are able to rent the home without any modifications.

That’s what sets Lile apart from the rest.

It’s been over ten years since Lile purchased and renovated his first house to rent to individuals supported in CL.

“That was my flagship rental. I spent over $11,000 making the house accessible. And I’m proud of it!” Lile beams.
Prior to buying that first property, Lile reached out to CL program Director Don Lafferty and inquired about the need for quality homes, and landlords, for individuals served in the program. After speaking with Lafferty, Lile leaped into action.

Lile understood that an initial investment into the property not only helped the individuals, but also led to a long term, low maintenance landlord-tenant relationship.

Lile is now a landlord for five individuals in CL, and a self-taught expert in Universal Design (UD).

Lots of research, studying designs, trial and error, and seeking local resources such as Services for Independent Living (SIL) have deepened his understanding of accessibility and universal design.

"I like to try different arrangements until I find what works. I’m an engineer. It’s what I do,” Lile says.

He takes the time to tend to his tenants and care for their homes. "After a person using a wheelchair has lived in the house for awhile, I will come in to take a look at the house to see where the chair has consistently bumped into the wall. I then repair and place a hard surface, such as aluminum, on those spots,” Lile says.

He is currently renovating a property for two individuals in CL. To make it accessible, doorways have been widened to 36 inches, a walk-in closet was made into an accessible shower, carpet was replaced with durable vinyl floor, and slow gradients were placed at each doorway, all within UD guidelines.

"The accessible shower took years to perfect. Leaking was a huge issue. We have the right design this time around," Lile says.

"Mr. Lile has been accommodating and VERY individual-focused to make sure that the environment meets the needs of the people moving in,” says CL Manager Carrie Griffith. “He’s been available and allowed us to tour the property multiple times to be sure everyone likes the property and that it's an appropriate match.”

Lile is an electrical engineer. He helps his tenants save serious cash on energy. In the house he is renovating now, Lile replaced the HVAC with a heating/air service that allows independent temperature control of each individual’s room. Lile has also installed special foam around windows and doorways where he’s identified air leaks using a special fan.

Lile was also willing to work with individuals on a monthly payment that works for everyone. “He has been able to negotiate the rent so that our individuals can afford it while still meeting his goals as a landlord,” Griffith says of Lile.

Lile also takes into account the employees providing support. In most CL houses, a staff person called a live-in, resides in the home too. Lile beefed up insulation to act as a sound barrier. This gives the live-in additional privacy when he or she is off the clock.

Griffith says of Lile, "It is incredibly difficult to find affordable, safe, and accessible housing in Columbia. He honestly has just been a pleasure to work with and we have been so thankful for this partnership."

“I like to try different arrangements until I find what works. I’m an engineer. It’s what I do,”
Tip from Tara

Let's all make some new paths!

Today I’m having one of those days when you are forced to think about something extremely difficult, stressful and hard simply because your time is up in delaying thinking about it.

I have to admit I hesitated in sharing what I am about to share, but I do so knowing that by sharing it maybe I can help another parent dealing with the same thing. That is after all the reason I write these tips every month, so here goes nothing…

Today I needed to finally respond to several emails regarding my opinion on the future plans for my son Rye. As most of you know, at least if you’ve read any previous tips I’ve written, that Rye is my twelve-year-old son who is differently-abled.

Rye is an amazing kid who happens to be on the autism spectrum. Rye is in sixth grade. It would be accurate to say that Rye’s transition to middle school has been pretty challenging for him.

Today, after spending the past few days thinking about what I’ve learned professionally over the past twenty-five years and feeling extremely thankful for all the professionals I’ve worked with, I finally responded to the question, “what are my thoughts concerning next school year?”

Here is what I said after discussing my thoughts on Rye’s current academic level and after outlining Rye’s opinion on the matter:

“I don’t really know what all the options are but I want what I’ve always want for Rye. I want him to feel happy and good about trying his best. I want him to learn and be a good learner. I want him to be prepared for a world as an adult that I eventually won’t be a part of and that is what is very scary for me (and every parent I know).

I want him to be able to work in a job that promotes his full potential as a person. I want more than sheltered employment. I want more than stocking shelves or cleaning off a table in the food court. I want him to start working on what he needs to know if he wants to go to cooking school, or become a construction worker, or maybe even a day care provider. He has many wonderful skills. He has talent. I worry very much he is not working on what he needs to work on now to be able to do any or all of these things in just 6 and a half more years.

I know that is all A LOT of big goals and dreams and hope for him discovering his full potential as a person. So… how do we get all of that into the IEP? I know I’m hard and expect a lot but thanks for continuing to support Rye’s dreams and ours! I do think all of this is possible if we find a way to help him make it happen!”

Today I ask all of you who work with, teach, or who parent somebody who is differently-abled to keep your dreams big, shoot for the moon. Everybody’s journey is different. Everybody learns differently. Being different doesn’t make anything impossible, it just makes the path to all the possibilities different.

Let’s all make some new paths!
When you walk around the Mizzou Athletics Training Complex (MATC) with Eli, you know he belongs there. He shows you around as if he runs the place. He knows everyone’s office. He knows where the players are in the building at all times. He knows exactly where his favorite players are honored on the walls.

And most importantly, he is knocking it out of the park with his job performance. He casually waves hello to everyone who passes, often times getting a “hello Eli” in response. You’d never guess he’s only worked there three months.

Finding meaningful employment for Eli was a no brainer for ACT Career Services (ACS) Career Specialist Dustin Murray. Eli has always been die-hard about one thing: sports. So Murray knew he would be a perfect addition to the staff at MATC. (You can read about ACS’s relationship with University of Missouri’s Sports Park here.)

As the sun rises over the athletic complex, you can find Eli preparing the building for another day of successes. He ensures the building is spotless for the athletes and coaches. This makes him proud.

He arrives at 5:00 am and starts his day by cleaning rooms where hours and hours of game tapes are reviewed and coaches hammered out their game day plans. He winds up his day dusting the pictures that pay tribute to Mizzou’s athletic greats, some of whom once roamed those same halls.

“My favorite place to clean is Barry Odom’s (head coach of the MU football team) office,” states Eli. “Do you want me to introduce you to him?” “My favorite thing about the job is getting to know everyone here!” He exclaims.

In his 90 days working at the facility, he has made quite an impression on everybody, professionally and personally.

“All the players and coaches know him on a first name basis,” says Sandra Frey, ACS Career Specialist. He might have been shy at first, but now there isn’t a stranger in the house.

MATC’s Lead Custodian and Hiring Manager for the cleaning crew Mike Lindsay adds, “He goes above and beyond expectations.”

Eli’s devotion to sports has gained him some notoriety in the past. A University of Missouri journalism student filmed a piece highlighting Eli’s involvement with the 2015 5A State Champion Battle Spartans. He was known by everyone as the team motivator.

Whether it was his position on the Spartans’ team or his outgoing personality, his popularity earned him the Battle Spartans 2014-2015 court-warming king, a first ever for the three-year-old school.

Now at MATC, it didn’t take Eli long to introduce himself to the newly-named head football coach and suggest he fill the position of head motivator on the Tiger’s roster.

Eli thrives alongside athletic figures he looks up to. Now he is getting paid to do it. And he’s excelling.

“He loves it!” Frey says. “He loves sports. So, this is a truly perfect fit. He has really blossomed there.”

Eli now receives very little support from ACS. As one who receives services from ACS grows into his or her position, the amount of time a Career Specialist provides job coaching decreases.

Soon Eli will no longer need support from ACS and Frey, who is down to one day a week for less than an hour. That is always the goal for individuals receiving services in ACS.

It can be hard finding one’s professional sweet spot. We are thrilled to have helped Eli find his. ACT will be cheering you on all the way, Eli! M-I-Z…! •
Daylight Savings begins on March 13.
St. Patrick’s Day is on March 17.
Spring begins on March 20.
Easter is on March 27.

Check our Twitter @ACTofCoMo and our Facebook fb.com/ACTofCoMo for more details.