



# The Bridge

Connecting individuals with disabilities and their families with resources, support and information



## LD Parents Connect

LDA of New York State, in cooperation with Tremaine Foundation, has a new resource for parents to connect with others while parenting a child with a learning disability or ADHD -- a new website called **LD Parents Connect**. Join with other parents across New York State who have the same concerns, joys and challenges that you do. Facilitated by an Educational Consultant, you can become part of the group and take advantage of a virtual support system from the comfort of your own home. <http://www.ldparentsconnect.org/>

## What's Inside...

This issue of *The Bridge* highlights Transitions: how to survive and thrive

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[www.advocacycenter.com](http://www.advocacycenter.com)

## Spotlight on Community

By Maria Schaertel

**Andrew Chinappi** shares a laugh with coworkers and chats at the front desk about sports, celebrities, and weekend activities. But when the phone rings, Andrew is all business. His is one of the voices that has greeted and guided phone callers for 11 years here at The Advocacy Center.

Andrew is very proud of his work and decided to highlight the experience in his testimony as a brand new Partner in Policymaking®. In his testimony, Andrew's main message was that people with disabilities can be successfully employed. "Nobody should tell you that you cannot work if you have a disability. I have been working for The Advocacy Center for 11 years. I answer the phones, and I like it very much."

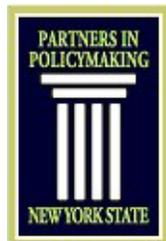
Co-worker Asim Javed, Intake Service Coordinator, mentored Andrew in the program and describes the experience: "It was great working with Andrew as his mentor in the Partners in Policymaking program. I saw Andrew develop in many ways. He displayed a lot of courage and perseverance every time we came across difficulties.



While he freely communicated his anxiety and concerns, ultimately he did not back away from challenges that confronted him.

Most notably, I remember one morning before heading to Albany, Andrew really did not want to go, and it seemed like I was going to make the trip alone. Nonetheless, Andrew overcame his fears, got in the car, and left Rochester for the first time in his life! Not only that, but during the whole trip back, he asked the following question, "So Asim, when are we doing this again?"

Congratulations, Andrew!



## Want to learn more about Partners?

Enrollment is now underway for the spring program. For more information on the New York State Partners in Policymaking program®, please visit: <http://www.nyspip.org/>.



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STRONGER  
TOGETHER!**

## Merger Update

The Advocacy Center and LDA Life and Learning Services continue to work together in preparation for our merger, slated for early 2015. Most likely even before the merger, we expect to move to the current LDA offices at 1650 South Avenue. The space is in a great location, and we look forward to working more closely with our coworkers at LDA.

We also expect to announce a new name for our merged organization sometime early in 2015. The name will reflect our identity as a new organization, respecting the legacies of both The Advocacy Center and LDA and looking to a bright future full of possibilities.

While we work behind the scenes to merge our operations, we continue to place the highest priority on meeting the needs of individuals with disabilities and their families. We appreciate your continued trust in us to meet your needs for information, support, and advocacy.



*Allyn*  
Allyn Stenjes

*Colin*  
Colin Garwood

For current news on the merger of The Advocacy Center and LDA Life and Learning Services, please visit our website: <http://advocacycenter.com/news-about-the-merger>



## Is there an Advocate in the House? Families Hold the Vision to Transition



**Laura Arrington**  
Parent Center  
Coordinator



In regards to special education, the term “transition services” means a coordinated set of activities for a child with a disability that is focused on supporting a student’s vision of a healthy, happy, productive adult life. In New York State, the process starts at age 15, but it’s never too early (or too late) to start helping your son or daughter develop a vision of life after high school.

Why do you need to develop a vision before starting transition services? Your child’s vision will be a road map to his or her life. If you don’t help and support your child’s unique vision, then someone else may be influencing and making decisions that do not support your child’s goals.

We can assist our children to explore their hopes and dreams by asking: Where do you want to live? Do you want to live with someone or on your own? What skills will you need to have to live

on your own? Where do you want to work? Will you work full time, part time, or volunteer? What do you like to do for fun? How will you get there?

Your child deserves to be part of the “real world.” By this, we mean the world of employment, community participation, and choice of living environment. If he or she is to participate in society, you need to think about the skills and supports needed to assure full participation. This critical information can help to drive transition planning and services. You and your child’s team can use this information to help develop the IEP (Individualized Education Program). The skills acquired will assist in developing appropriate goals for successful adult outcomes. You and your child will always be tweaking the vision, so it should be a continuous piece of work that grows along with your child.

Give your child permission to dream: Dream for today, Dream for tomorrow, or Dream for the next milestone or birthday.

**LIFE IS CHANGE.**  
**GROWTH IS OPTIONAL.**  
*Choose wisely.*

– Karen Kaiser Clark

# The Advocacy Center Upcoming Events & Workshops

*Please note location varies for each workshop.*

**REGISTRATION IS REQUIRED for all workshops.** To register, please find the event on our website calendar ([www.advocacycenter.com/events](http://www.advocacycenter.com/events)) or phone (585) 546-1700 ext 399.

## Discipline and Suspension

**January 22, 2015, 7:00-9:00pm**

AutismUp, 180 Linden Oaks, Rochester, NY 14625

Children with disabilities have specific rights under state and federal laws regarding suspensions and school discipline. This workshop will provide an overview of these rights and the process used for discipline and suspensions. Participants will learn about Functional Behavioral Assessments and how to create a proactive behavior management plan to help avoid future conflict.

\* \* \* \* \*

## IDEA (Individuals with Disabilities Education Act)

**February 10, 2015, 7:00-9:00 pm**

AutismUp, 180 Linden Oaks, Rochester, NY 14625

Children with disabilities are entitled to appropriate, individual educational services that meet their unique needs. This workshop will explain the history of the Individuals with Disabilities Education Act (IDEA) and the Family Education Rights and Privacy Act (FERPA), two federal laws that govern education for students with disabilities. Families will gain information on the laws regarding their children's rights to an appropriate education.

\* \* \* \* \*

## Managing the Move: Preparing for Next Year

**March 14, 2015, 10:00am-12:00pm**

Happiness House, 731 Pre-emption Road, Geneva, Ontario County, NY 14456

Moving from one school year to the next can be challenging for families and new team members. This workshop will provide parents and other team members with strategies to help promote a seamless transition and lay the groundwork for a positive start to the new school year.

\* \* \* \* \*

## Pro-Social Sexuality

**March 18, 2015, 7:00-9:00pm**

Penfield SEPTA, Bay Trail Middle School, 1760 Scribner Rd, Penfield, NY 14526

Teaching individuals with disabilities about sexuality is important in promoting independence, personal safety, and social inclusion. Families will gain a better understanding of teaching their son/daughter public and private behavior, and be able to address the topic of sexuality with their children teens, or young adults with disabilities.

## Webinars

\* \* \* \* \*

### IEP Essentials

**Tues., January 13 - 12:00-1:00pm**

When a child qualifies for special education services, federal law requires the development of a document, called an Individualized Education Program (IEP). The IEP serves as a road map for services, including important information about a child's levels of performance and needs, as well as goals for the child. This webinar will prepare participants to actively participate on the IEP team.

**REGISTRATION IS REQUIRED.**

To register, go to <https://attendee.gotowebinar.com/register/5459279004036480769>

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### Preparing for the Annual Review

**Tues., February 10 - 12:00-1:00pm**

An annual review is a Committee on Special Education (CSE) meeting to plan for the next school year. This webinar will help families prepare for annual reviews. Topics to be covered include pre-meeting preparation, development of an Individualized Education Program, and tips to help parents and educators collaborate in designing an appropriate program for a student.

**REGISTRATION IS REQUIRED.**

To register, go to <https://attendee.gotowebinar.com/register/6760755524672580353>

\* \* \* \* \*

### Lunch and Learn 2015

Please check the website calendar at [www.advocacycenter.com](http://www.advocacycenter.com) for upcoming springtime "Lunch and Learn" sessions. Date and location details will be provided upon availability. For further information, please call (585) 546-1700 ext. 399.

## Creative Teaching Tool

by Maria Schaertel

Parent and Distance Learning Coordinator/Advocate, Gretchen Jackson, created a unique visual aid to help her son, Joe, grasp the idea of death and what happens when a person dies.

Based upon their family's belief that humans are made of both body and spirit, Gretchen creates a paper doll, drawing features to match the person who dies. The doll consists of a paper front and separate back with a piece of matching wax paper in between to symbolize the person's spirit. She slips the wax paper from inside the regular paper to show the spirit rising from the body.



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## Writing the Next Chapter

By Seneca Brashear

A school counselor told me a few years ago that, while it was understandable to want to keep the world perfectly safe and steady for my children, change is a fact of life. Teaching children how to cope with change – particularly unwanted developments like divorce or death – teaches them resilience and flexibility, which will serve them well their whole lives. To make that possible, I encourage my children to identify their feelings honestly, and to talk with me so they understand that it is okay to feel what they feel. And then we work on how we get through that moment to find a brighter next stage. I tell them, “This isn't the end of the story. There is a next chapter and we have a choice in how we write it.”

# Transition: How to survive and thrive

## Lessons Learned from a Year of Transition

By Allyn Stelljes, Deputy Executive Director, The Advocacy Center

It has been almost a year since we announced that The Advocacy Center and LDA Life and Learning Services were affiliating with the intent to merge. During this year of organizational transition, I have learned and observed a few things related to the theme for this issue of *The Bridge*: “surviving and thriving.” Here are my thoughts, along with questions that may help you if you are experiencing a transition or planning for a personal or organizational change.

### Change always involves letting go

The first thing lesson I learned (or re-learned) is that all transitions involve some necessary “letting go” of the old reality in order to make room for the new. With any change, even with very positive change, people experience a loss. It is a necessary step to make room for the new reality. This perspective has helped me to honor our organization's roots and at the same time prepare with excitement for our future.

*Have I taken time to appreciate my past or current circumstances? Am I allowing myself to let go?*

### We are stronger together

I have had many opportunities this year to observe the power of teamwork. Staff and board members from both organizations have stepped up to work together on various aspects of the merger, while also making sure that the daily work of accomplishing our mission has continued. Over the course of the year, we have discovered how much we all have to offer each other. We have also reached out to community partners, like the Ad Council, United Way, and New York Council On Nonprofits (NYCON), to assist us. We have benefitted from their expertise and experience. It really is true that we are stronger together.

*In what areas do I need assistance? Who has valuable expertise to offer?*

### Know yourself

Another lesson I learned is the value of knowing who we are and why we are here. Earlier this year, we engaged in a brand development process as the first step in forging our identity as a new organization. Board and staff from The Advocacy Center and LDA Life and Learning Services participated in the process. Our brand platform defines who we are and serves as our foundation. It also helps to remember, above all, why we are here, and that is to support individuals with disabilities and their families.

*Am I clear on what is important to me and/or my organization?*

### Stay well

My final lesson is important always, but especially during times of change. We need to take care of ourselves and stay well. In a way, our plans to merge are a manifestation of our desire to maintain organizational vitality. As individuals, we also need to take good care of ourselves physically, mentally, emotionally, and spiritually; whatever that means to each of us. When we take care of ourselves and focus on what is most important to our mission, we do more than survive. We thrive.

*As an individual, what can I do today to take care of myself? As an organization, what do we need to do to stay healthy and vibrant?*

## Letting Go of Grown Children

By Julie Buick

Change and loss for our family is code for a process known as letting go. With change comes growth, which has been evident this year specifically with my daughter, Kathleen. She is 20 years old and decided it was time to make a change and move out. My boys, Billy (15) and Bobby (12) both have FragileX and Autism. Like most kids, Bobby and Billy don't care for change, especially when it affects their family dynamic and what they know to be secure and the norm.

Kathleen's decision to take a leap has not only affected her, but it has also affected our family unit, creating a loss and triggering the grieving cycle. With any shake-up, we have days of great sadness, uncertainty and resistance. My boys are in touch with their emotions and have some key people at school that they can talk to. They never keep what happens at home a secret, so it was important for them to be able to express the change with those at school and talk freely about how this change affects them. We are lucky to have a supportive and collaborative team for the boys at school.

As the days went on, individual grief became group grief, in which we shared our fears over the change and began to explore together how we could respond creatively... Billy likes to write his feelings down as they develop and then share with us, while Bobby will just freely discuss as things come up. My husband, Bill, and I have learned that we have to go with the flow and be there when the timing is right for them. We are lucky to have a nice support system, as well, to help keep us balanced and able to move forward. It's so important as a parent, especially one that is raising a child or children with disabilities, to remember self-care and asking for help. Especially since

asking for help is a work in progress for most of us.

We have been a family of five for so long and have grown comfortable with that. It helps us adjust to the change to recognize that there is something kind of awesome and adventurous about now being a family of four with a visiting sibling and daughter. Having a sense of humor also helps us cope: For one, the idea of a smaller car with better gas mileage comes to mind! Now, when we go out to eat, we can ask for a booth because four people fit nicely in a booth. And it is only fair that I ask the question, "So how long does one have to wait before claiming their daughter's bedroom once she moves out"? We all have ideas for this space, like an art studio for me... The laughter and joking helps us to let go, change perspective, find gratitude, and see new ways we can still be a family even with a sibling who doesn't sleep in our home anymore.

Kat can't stay away for long and has been back to spend the night on a few occasions, opting for the family room couch. She came over to visit with a few of her friends for Halloween and to take the boys trick-or-treating. Absence really does make the heart grow fonder, and the kids seem to get along way better these days with much more gratitude for one another and the gifts they bring. Our family unit is benefiting from being together in a more intentional way where everyone honors one another and enjoys the time we have to be a family of 5 again.

It's a work in progress and the change is one that is benefiting our family in ways we never thought possible. Change is good!



## A Labor of Love

by Maria Schaertel

"We don't talk about it. We don't plan for it. It's going to happen."

When Family Advocate and Trainer and parent, Norann Shiner, supported a family who experienced a sudden death, she witnessed how painful it was for the child with a disability to understand and cope with his father's death.

That day, Norann had an idea for how to ease the grieving process and possibly even foster understanding. She thought about her own son with a disability and how he would cope under similar circumstances. Not well, she decided. "Why not create videos for our children for when we are gone? Who better to help my son cope than myself? It could give him something to go to when he is distraught."

Norann attempted unsuccessfully several times before she could compose herself enough to complete the project. She created three videos for her son, Adam: one to be seen upon her death, the next to be seen two months later, and a third to be seen four months later. In the videos, she addresses her son and explains to him why she is no longer able to visit with him. She guides him to go to the people in his life for help. Norann says, "Who better to say, 'it's ok to cry and be angry' than his mother?"

"Every family will have a different approach for steps to help in times of loss and transition. But it is vital to have a plan in place -- not just for children with disabilities, but for all children."

# Thumbs Up!

To Asim Javed for mentoring coworker Andrew Chinappi through the Partners Program.



Andrew and Asim

*Personally, I saw a lot of growth in myself over the past 8 months. As Andrew's mentor, I learned to be creative and flexible when it came to supporting his needs. Through the months of meeting as well as traveling to Albany together, our relationship developed beyond a mentor and mentee or co-worker relationship, to a strong friendship. Andrew's zeal for advocacy has inspired me in many ways to be more assertive in my own relationships.*

*I am proud of Andrew and believe he will truly succeed in his Partners goal of becoming a self-advocate for individuals with disabilities.*

Asim is currently completing his Masters degree in Mental Health Counseling at the University of Rochester. In the past several years he volunteered as a research assistant for multiple autism studies through the University of Rochester. Asim has developed a strong interest in working with individuals with disabilities.

## NYS Partners In Policymaking News

by Jackie Yingling

Exciting transitions are taking place within the NYS Partners in Policymaking program.

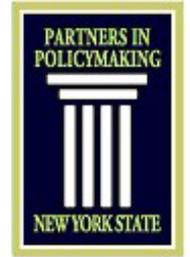
Enthusiasm was in the air this past fall as participants in the NYS Partners in Policymaking program became graduates of the course. As a culminating activity, 31 Partners presented a short testimony about a disability-related subject at testimony/graduation sessions. The sessions took place in Queens, Rochester, and Schenectady in October 2014.

During the course, participants gain the knowledge, skills, and confidence to make changes in policy, perception, and treatment of individuals with disabilities. Upon completion of the program, they become part of a graduate network.

The course is offered as a series of interactive modules and webinars, with one state-wide and one regional in-person meeting. The program focuses on including self-advocates and individuals from diverse backgrounds, and on developing participant's familiarity with technology and on-line communication tools for advocacy.

The Partners have been working together since Feb. 2014. Congratulations to all 55 graduates!

Want to become a NYS Partner? Fill out an on-line application. Go to [www.nyspip.org/](http://www.nyspip.org/) and click on "I want to apply". The course starts again in Feb. 2015.



◀ Schenectady graduates.



New York City graduates ▶



◀ Rochester graduates

**New class starts Feb. 2015!**

## From the Editor

Christmas won't be the same this year. Grandpa's blue recliner will be empty, and the void will hurt during our annual breakfast gathering and gift exchange. My son, Nick, has been lucky enough to know all four of his grandparents. For 22 years, they have been a part of birthdays, holidays, vacations, and many of the days in between. Losing one of them is not easy. My husband's dad, Peter Schaertel, died on Wednesday, October 29.



Nick and Peter Schaertel

How do we help Nick through this life transition? The way in which we do this is incredibly important. We need to sustain Nick through this change and also realize he will use this experience as a reference for future life changes.

Our family's belief in heaven is a great comfort for Nick. But a distant, abstract notion of heaven will not suffice.

Since Nick is a visual learner who understands ideas better when images accompany them, "heaven pictures" are very helpful. When Nick was younger, we used picture symbols, drawings, and photos to illustrate concepts. But now, we can just talk about what heaven is like and Nick "sees" the images in his mind. As Nick says, "Grandpa's eyes are open again in heaven." I follow Nick's lead and supply more images: "Grandpa is walking again in heaven. Grandpa is singing again. He is not sick anymore!" Nick brightens at the thought of Grandpa being healthy again, even if he is not here with us.

My father in law always made his presence known, either through

his booming speaking voice, his wonderful piano playing, or his powerful, beautiful singing voice. Nick knows Grandpa won't be here with us anymore, and he already feels that void. Days after the funeral, when visiting at Grandma and Grandpa's house, Nick went upstairs to check out Grandpa's room. He came downstairs and confirmed, "He's gone."

My inclination is to shield him from the pain, but I am learning it is OK for Nick to experience loss and grief. He will hurt, cope, and then thrive as we all do. Time will help.

*Happy Holidays and Happy New Year to all.* Enjoy your families and friends, your unique traditions, and hopefully, some relaxation as well.

See you in the spring with the next issue of The Bridge. In early 2015, The Advocacy Center and LDA Life and Learning Services will officially merge and will announce our brand new name. Looking forward to this exciting transition!

*Maria Schaertel*



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## The Bridge has Gone Green

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**Upstate Special Needs Planning**  
Preserving Choices

**James Traylor, President**

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