

# Family Support Network

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## Let's Do Together What We Can't Do Alone!

Hello Family Support Network Family and Friends,

First, let me just tell you how grateful I am to all of you for your continued commitment to the Family Support Network and to its mission and core values. Whether we are self-advocates, family members, or professionals who work with people with intellectual and developmental disabilities, we all want the same thing – individual-driven high quality community services and supports for people with ID/DD and their families – services and supports that allow people to choose the life they want to live and to choose the home that suits them best. We can't put too high a price on this, yet every year there seems to be some sort of budget crisis that's doing just that – making the cost of vital services and supports a political issue and making people with ID/DD pawns in a political conflict.

This year is no exception. The ups and downs of the budget situation are unlikely to be resolved before you receive this issue. As you know, the Family Support Network had to suspend services for a little while this spring because funding was stopped and then renewed. I don't want to sound like a broken record, but it's really important to let

your legislators know what's important to you. Sometimes we don't realize how critical local and state politics are. Many decisions that impact our loved ones are made on the state level. Please continue to cultivate a good relationship with your state legislators. Most of them are more approachable

than you might think and they genuinely want to hear from you, especially if you are a stakeholder whose services are directly affected by budget cuts.

The Family Support Network is all of us. Your role is as crucial as our staff's is to its continued existence. Please keep in touch. Please contact us with questions or concerns or suggestions. On our part, we will continue to do everything we can to advocate for services for adults and children with disabilities in Illinois. This means keeping individuals and their families informed – bringing in speakers on topics of interest to individuals and their families, creating events that offer opportunities for individuals and their families and professionals to network productively, participating in and supporting events hosted by other organizations that educate individuals and their families, and sending out newsletters and updates on news items and policy changes that are relevant to people with ID/DD and their families. And, as always, we will continue to not only advocate for individuals and their families, but we will continue to support the development of family advocacy in Illinois. We are family members who struggle with many of the same issues some of you struggle with on a day to day basis.

If you are not a member of the Family Support Network, please join today. For information on how to become a member, visit our website at [www.familysupportnetwork.org](http://www.familysupportnetwork.org). Join forces with other families who are making a difference!

Sincerely,

**Shirley A. Perez**

Executive Director, Family Support Network of Illinois



Shirley Perez

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# Ligas Consent Decree Reaches Four Years of Implementation



Tony Records

The Ligas Consent Decree was ordered by the Court on June 15, 2011. The Decree calls for the infusion of significant new resources for community-based services and provides for

thousands of class members and their families to have choices of how and where services will be provided. The Decree also calls for people with developmental disabilities (class members) who live in privately-operated ICF/DD facilities to receive funding to transition to community-based services if they choose to do so. Since the signing of the Decree, more than 2,300 people with developmental disabilities who were on the PUNS waiting list are now receiving community services and supports funded through the Illinois Medicaid Home and Community-based waiver. Families have often rejoiced when they received the "Ligas Letter" which indicates that their loved one was chosen to receive funding for services. Some people who were chosen for

services have been waiting for over ten years. A large majority of the people who were selected to receive funding have chosen the home-based option, thus electing to stay living with their families and receiving ongoing supports. In addition to the class members coming off of the waiting list, more than 1,150 people who once lived in an ICF/DD facility have since transitioned to community-based services and are now living their lives in a new home they chose.

All class members who move are entitled to a written Ligas Service Transition Plan. This person-centered document is now used for any Ligas class member who is selected for funding for community-based services and who moves from one location to another. To learn more about this planning process see the Illinois DDD website. The Council on Quality and Leadership (CQL) is fully implementing activities for people in ICFs/DD to help families and potential class members who have not yet made a choice learn about their options about how and where services can be provided. More than two thousand guardians of

potential class members have been initially contacted to determine their interest in community options.

Some families of individuals who have been chosen for funding under Ligas have continued to express frustration with the limitations and lack of flexibility in the home and community-based waiver, particularly as it applies to smaller residential options as well as options for employment related day supports. DDD, in conjunction with the Ligas Monitor has formed a Class Member and family Advisory Council to learn more about the experiences for families in the Ligas process and respond to their concerns. Two members of the Ligas council are Ligas Family advocates. The Arc/FSN Ligas Family Advocate program is up and running – sharing information with families about options and creative ways to use their funding. You can contact a Ligas Family Advocate by calling 708-331-7370. Comments or complaints about your experience with the Ligas process and services or to find out if you are a Ligas class member should be directed to Troy Markert at DDD. He can be reached at 217-785-6171 and [troy.markert@illinois.gov](mailto:troy.markert@illinois.gov).

## Best Wishes to Tony Records as he retires!

### Reflections of Gratitude!

FSN and the Ligas Family Advocate Program (LFAP) congratulate Tony Records on his upcoming retirement. Since 1992 Mr. Records has been the President of Tony Records and Associates, INC. (TRA) a human services consulting firm in Bethesda, Maryland. He has 38 years of experience and has consulted in 22 states with regard to services and supports for people with disabilities. He came to Illinois to serve as the Monitor of the Ligas v. Hamos case with an outstanding reputation in the field and he has proven to be the dedicated and knowledgeable expert we expected and more.

What will resonate with the individuals and families who read this newsletter is his perseverance in carrying out both the letter and the intent of the settlement. He has brought in experts in the field to educate families, providers,

and professionals. He has initiated programs (like our own LFAP) and worked closely with them. He has made himself accessible to families at countless events, but also one-on-one. He takes his court monitor title seriously and he has continually monitored to assure that not only is the Ligas settlement meeting expectations, but it is exceeding them. We will miss his ability and expertise, but we will especially miss his heart for people with ID/DD and their families.



# Photos from state-wide Know Your Options Events

June 23, Forest Park, IL • September 16, Alton, IL



Tony Records, we wish you a life surrounded by those you care about most, something you have worked hard to achieve for the Ligas class members and their families.

Sincerely,

The Arc Ligas Family Advocate Program





## Ligas Family Advocate Program

The Ligas Family Advocate Program (LFAP) of the Arc of Illinois is a relatively small and extremely cost-effective family-to-family outreach to Ligas Class Members and their guardians and families that has a giant impact on the Developmental Disabilities (DD) system. In fact, it was created because there were unmet needs of Ligas class members and their families, especially those new to the system, to receive consistent information about options and to receive support connecting with other families. LFAP provides a unique and instant personal connection for Ligas class members and their families to other Ligas class members and their families who are just beginning their Ligas journey, as well as to more experienced families who have navigated the DD system and can offer their firsthand experience and support in a way that enhances but does not duplicate the work of the Independent Service Coordination (ISC) Agencies. On the contrary, the LFAP is a resource for ISC Agencies and their already overloaded caseworkers, who may have a wide variety of assignments besides Ligas related responsibilities. Family-to-family outreach to Ligas Class members and their families is what LFAP was designed to do.

### Resource for Families and ISC's

Unlike the ISC's The Arc's programs provide families and individuals with expert advocacy resources in many areas important to Ligas class members and their families, including employment, special education, civil rights, criminal justice, public and private insurance benefits, person centered planning and much more. These resources were never available before to families. When families first learn their loved one is a possible recipient of services due to Ligas class member status, they are often overwhelmed by the choices available and can easily fail to understand the importance of the Ligas settlement for

their loved ones. Many of these guardians/caregivers are aging and many have been waiting for years for services. Contact with a Ligas Family Advocate who is a family member and who understands the system and can direct families to assistance in areas the ISC's don't cover (such as help in obtaining SSI or Medicaid benefits, for example – or other necessary documents, which are an important piece of the process) is priceless. LFAP hosts informational events, such as "Know Your Options," that give families a chance to directly connect with other families facing the same issues and complex choices.

### Staffing

The program director is a parent of an individual with disabilities and has over thirty years' experience working in the DD field including eight and a half years at an ISC. Every Ligas Family Advocate has a combination of professional experience and a critical family component. They are all experienced stakeholders in the DD system, who know that family advocacy is necessary and tough choices have to be made every day to juggle responsibilities as family members and professionals and to empower their loved ones to live a full life. This unique family component makes LFA's particularly accessible to families and gives LFAP staff an ability to empower Ligas class members and their families in a way that can only strengthen family advocacy in Illinois, an area that has long needed this support.

### Data Resource

Working with and conversing at length with Ligas class members and their families allows LFA's to collect data on the barriers Ligas class members and their families are encountering in their search for individualized services. This data is shared with the Ligas Court Monitor and the IDHS Department of Developmental Disabilities and can be used to identify areas of concern and

drive positive change in Ligas implementation and in the Illinois DD system.

### Impact on DD System

Without a true understanding of the options available and without the support of other knowledgeable families, we fear that Ligas class members and their families will fall through the cracks. They may make poorly thought out decisions and choose to simply keep their loved one at home and continue to care for them without help. A warning sign that's already apparent is the number of Ligas class members (561) who have received letters of invitation and completed the pre-admission screening process and been found eligible, but so far have not accessed services. Ligas class members are then missing out on opportunities and their families are at greater risk for burnout and the kind of despair that can lead to neglect or drastic decisions that could harm or even end the life of their loved ones.

This kind of long-term care by aging guardians without critical supports can lead to crisis status for many individuals-creating an unnecessary burden on a DD system that already has a waiting list of over 22,000. This is a problem that will only be exacerbated in the coming years as more people age into Ligas eligibility and are invited to participate as a result of future PUNS selections. The end result could be a system that is not able to meet even the basic needs of consumers and their families.



Irene, Shirley and Katherine

# Photo Highlights

## Family Support Network Informational Seminar March 26, 2015 Heritage Plaza Banquet Facility

Thank you Pastor Alan Ragland and The Third Baptist Church of Chicago for partnering with the Arc of Illinois Family Support Network! PowerPoint presentations can be found on our website

### Presenters for the event:



Sherri Schneider



Cathy Yadamec



Craig Morrison



Tasha Whiteside

### FSN Highlights: March 26, 2015 at Heritage Plaza Banquet Facility



Rak and Kimberly



Janet and Sarah



Halima Jabulani, Arc Board



Rose, Lydia and Cynthia



Marylynne and Sarah



Cynthia Justice, FSN Assistant



The Arc team and volunteers



TBCOC Security/Support Team



Missy, Tony and Toni

## The Arc of Illinois – Still At Risk!



Deb Fornoff

As you may be aware, the Illinois Life Span Program grant was not included in the Governor’s proposed budget for fiscal year 2016. Our funding was eliminated along with many other grant funded programs including the Illinois Association of Microboards & Cooperatives and The Autism Program, to name a few. The Illinois Life Span grant funds the Illinois Life Span Program, The Family Support Network, and the Family Transition Program of The Arc of Illinois. Although funding for this and other grant programs is included in the budget passed by the House on May 26th, we will not know the future of Illinois Life Span until the Illinois budget plans have been finalized.

Illinois Life Span provides information via their website at [www.illinoislifespanspan.org](http://www.illinoislifespanspan.org), through their toll-free line at 1-800-588-7002, and via e-mail at [info@illinoislifespanspan.org](mailto:info@illinoislifespanspan.org). Fourteen years ago, the Illinois Life Span Program was implemented as an investment of the Illinois Council on Developmental Disabilities. This program was developed to meet the need for a “one stop shop” for information related to advocacy, services, and supports for individuals of any age with intellectual and developmental disabilities and their families statewide. Before Illinois Life Span, there was truly nowhere for families to turn for help with the broad array of questions that arise about systems, services, and supports.

Families that include a loved one with I/DD face daily challenges, and the challenges change, but persist, throughout the lives of their loved one. When our children are young, we learn about the diagnosis and begin to understand a whole new language related to disability services and supports. We address medical and developmental needs. We learn about the CFC, EI, IFSPs, PT, OT . . .

Throughout the school years, families need to

know about their rights within special education and who to call for help when there are problems. We learn about the teaching methods and learning strategies that work best for our children. We advocate. We often find support and learn from parents who “have been there” before us through support and other advocacy groups. We learn about IDEA, IEPs, LRE, ISBE, the PTIC . . .

At no point in our lives are we ever “caught up” when it comes to our education on behalf of our loved ones. We think about transition and plan for employment as our children move through the education system. We have to prepare for the future of our children with disabilities very thoughtfully and with support from well-informed professionals. We have to know about the adult system of services and supports and why PUNS is meaningful. We learn about benefits, eligibility, and redetermination. We learn to work with our legislators and policymakers to improve opportunities and expand vision. We need to know about the ISC, SSI, DDD, DRS . . .

Although a place to call for information and resources may sound like a simple service, if you don’t know where to turn, it can be critical. Known as the “411” for disability information, this program helps find resources and assistance for the broad range of issues that families experience in their journey through these multiple, complex systems. Illinois Life Span has been there for 14 years to share information and direct Illinois families to the resources available to answer their questions, concerns, and provide the services they need. Please let your legislators know that there is still a need for this important service and that you support continued funding for Illinois Life Span!

Deb Fornoff, Director  
Illinois Life Span Program

## Raffle Winners from FSN’s Informational Seminar

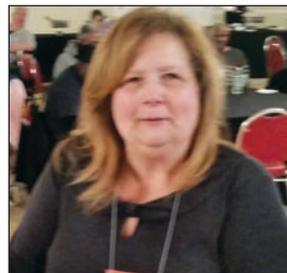
March 26, 2015



Lucia and Perry – Danville, IL



Becki - Bourbonnias, IL



Laurie – Joliet, IL



Olivia - Chicago, IL

# Photos from the Arc's Leadership Conference

with Rep. Patty Bellock - February 5-6, 2015



# Photos from the Arc Convention

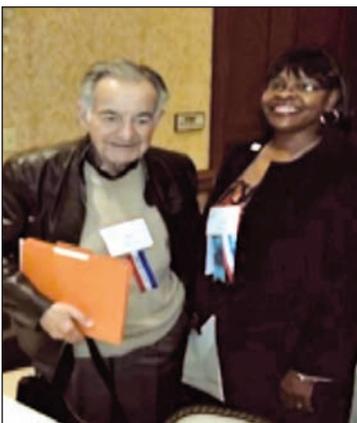
April 22-23, 2015 at Lisle, IL



Terri and Vicki



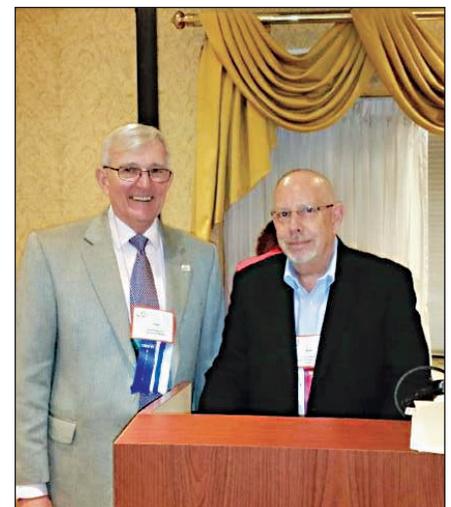
Derrick, Shirley, Mark and Michael



Walter and Shirley



Tony and Shirley



Tony and Brian



Katherine Hamann

## Family Transition Project

The word "family" is in our "Family Transition Project" name, because - just like the Family Support Network - we believe that families are critical in the life

of people with intellectual and developmental disabilities. Families really are the definition of "natural supports." We advocate for our loved ones with ID/DD, we support them in every way we can, we participate in their struggles for a life that fulfills their hopes and dreams. Sometimes we have to speak up for our loved ones. Sometimes we have to hold back and watch them experience life for themselves because ultimately that's healthy and empowering. Sometimes we are so frustrated we could cry. But whether we are self-advocates, siblings, or parents or guardians, we gain strength from each other and we learn from each other. This is why what the Family Transition Project (FTP) does is simple to explain, but potentially very powerful. We connect families who have experienced their loved one's successful transition from institutional

living to families who are considering helping their loved one transition from an institution or who are in the middle of the process or who have not had success and are looking for help. So, we're always looking for families with positive stories to share and for families who need that family-to-family support.

Families know that situations can change in a heartbeat. Funding can fall through, a provider may be unable to provide what our loved one needs, staff and policy changes can unsettle our loved one's life, or changes in our loved one can make changes in their services and supports necessary and even urgent. As a guardian and sibling, I know firsthand that feeling in the pit of my stomach when my sister Margaret's QIDP or house manager or medical staff call and leave a message for me to call back. She's doing great in her 8th year of living in the community (after 63 years in institutions) but she is 72 now and like all of us she has some health issues that need to be monitored. It's always just pure joy to me to visit her and see that all is well in her home and that she seems to be happy with her life. This is why one of the happiest things we do at FTP is following up with people who have

shared success stories with us and finding that they are not only still doing well, but are doing better than before.

This year the FTP had that experience a number of times. I particularly remember a trip to southern Illinois where I met two men who used to live at the Warren G. Murray Developmental Center and now live in homes provided by Centerstone. I had met both of them about a year and a half ago, and both of them were not only still doing well, but they both were excited about sharing with me some of the positive changes in their lives. One of the men had a lot more "outside" work (outside of his sheltered workshop) and a steady girlfriend and some new possessions that he purchased with his earnings. And, oh yes, he still is not smoking after over two years. These are things anyone would be justly proud to relate. The other man feels he has matured and has a better attitude. He is in a self-medication program now and also is earning more money for hobbies and trips (he's already taken some). He loves animals and now has some shared responsibility for a dog. I met a number of other people on this trip who were doing well in their new lives in the community. One man, about

The Arc Family Support Network of Illinois thanks **Uli Senz** of **Genesee Lake School** for being the first vendor to register for our Informational Seminar three years in a row!

*Thank You!*



my sister's age, has never lived outside of an institution since childhood, and he is adjusting extremely well, particularly to home cooking. A woman who once lived at Choate told me that what she likes about community living is "everything." A woman who once lived at Lincoln and talked to me reluctantly the first time we met asked me when we met again to visit her and see how well she is doing in her own apartment. Some self-advocates I met who have their own apartments talked about friendships they have made and about having their own homes decorated the way they like.

The Family Transition Project continues to be involved with the Going Home Campaign and the new Going Home Community Inclusion Coalition. The Coalition is a more independent offshoot of the Going Home Campaign and its members are self-advocates and various like-minded organizations who support community living (and full inclusion) for people with ID/DD. It's been exciting this year to watch Going Home (and particularly the Going Home Advocacy Day) follow the direction of self-advocates who are passionate about having a full life in

the community. A friend of the Family Transition Project who lived at the Howe Developmental Center for some years and now enjoys his CILA (Community Integrated Living Arrangement) home was a speaker at the Going Home Rally. This was his first experience at public speaking and he started out with a speech in the Capitol Rotunda. He was proud of himself and we were proud of him for remaining unflustered and getting his point across.

The Family Transition Project continues to be involved with visits to legislators to spread the word about community inclusion and this produced some very encouraging experiences. There were several visits by legislators to homes in the community where they were able to see that people with many challenges can succeed with the right support. One legislator contacted the FTP about families in her district whose loved ones with ID/DD needed services. This is one of the many times we appreciated the team work of our colleagues at Illinois Life Span, the Ligas Family Advocates Program, Family-to-Family, and the Family Support Network - all programs of the Arc of Illinois.

Provider Expositions at the Elizabeth

Ludeman Developmental Center and the Choate Developmental Center were a unique opportunity for the FTP to meet self-advocates and families who might not normally attend some of the many informational events sponsored by The Arc of Illinois and its various programs, because they are not necessarily informed about community options or even in favor of them. Families have unfortunately been polarized by the fight to keep state operated centers open and I heard a number of comments from families like, "I'm here incognito," and "Do we have to make a decision today?" and over and over again - "it (Ludeman or Choate) is not closing is it?" Yet other self-advocates and families were clearly interested in exploring the possibilities. They were just concerned that they might not find the options or the stability they needed. So it was a chance for some good discussion.

The Family Transition Project is here for families whose loved ones have experienced a transition to the community from an institution or who want to transition or who just have questions about it. Please contact me at [Katherine@thearcofil.org](mailto:Katherine@thearcofil.org) or call me at 708.465.2827.

## Wings For Autism • May 2015





# What are the functions of the various bureaus/areas within the Division?

## Community Services

### Bureau of Regional Services

- Meets with the Independent Service Coordination (ISC) agencies' Program Managers quarterly to discuss, clarify, and resolve service system issues along with the Bureau of Transitional Services, when needed.
- Addresses and resolves ongoing inquiries and concerns from individuals with intellectual/developmental disabilities, guardians, families, advocacy groups, legislators, and/or DDD-funded agencies regarding the service delivery system.
- Reviews and processes Waiver and Purchase-of-Service funding request packets, Service Termination Authorization Requests, Bed-Hold Requests, and Temporary and Ongoing Additional Staff Support Requests.
- Participates in the Multi-Agency Clinical Staffing (MAC) process to ensure that eligible individuals are linked to needed in-home or residential services.
- Forwards Department on Aging (DoA) Adult Protective Services' referrals to the local ISC agency for follow up activities. Monitors the ISC agency's follow up activities.
- Requests local ISC agency conduct on-site wellness checks to the individual's residential setting or home .
- Provides technical assistance to funded agencies that are experiencing either short or long term financial difficulties.
- Reviews, processes, and tracks Individual Service and Support Advocacy (ISSA) agencies' requests to exceed the 25-hour ISSA allocation per individual receiving Waiver-funded services as a result of the individual's medical and/or behavioral issues.
- Facilitates local Clinical and Administrative Review Team (CART) meetings and initiates Service Support Team (SST) referrals regarding children and adults with intellectual/developmental disabilities who are exhibiting medical and/or behavioral issues, and makes appropriate recommendations in order to maintain the person's community-based services.
- Assists and tracks individuals who currently reside in State Operated Mental Health Hospitals (SOMH) transition to DDD-funded community based services.
- Monitors and tracks the closure of CILA settings.
- Conducts Exceptional Care SNFs/Ped desk and on-site clinical reviews.

## Community Services

### Bureau of Transitional Services

- Facilitates community based transition opportunities for individuals with intellectual/developmental disabilities who reside in State Operated Developmental Centers (SODCs).
- Monitors the delivery of technical assistance to individuals with developmental disabilities, their family members/legal guardians, and service providers in order to ensure a smooth transition.
- Facilitates community-based transition opportunities for Department of Children and Family Services' aging-out youths.
- Reviews and processes Medicaid Waiver funding requests along with temporary or ongoing additional staff supports.
- Provides follow up and monitoring on site visits after individual transitions from SODCs for 12 months post transition to an alternative community based residential setting.
- Works closely with ISC agencies, community providers and SODC staff in determining placement barriers, securing new opportunities, and overall transitional process.
- Facilitates the SODCs' community placement meetings with SODC staff member and local ISC agencies.
- Generates SODC monthly reports (e.g., Tier Report, Monthly Net Census Reduction Report).
- Monitors statewide compliance of Money-Follow-The-Person (MFP) mandated activities for persons who transition from institutions (SODCs and privately-operated ICFs/DD) to 4-person CILA settings. Generates ongoing MFP reports.
- Ensures compliance with Ligas Consent Decree's benchmarks (i.e., reviews and processes funding requests for eligible class members, tracks transition activities, resolves issues prior to the individual beginning services.
- Monitors and tracks the downsizing or closure of privately operated ICFs/DD.

## State Operated Developmental Centers Operations

- Manages the operations of seven residential centers including one forensic unit for individuals with developmental disabilities.
- Coordinates admission, discharges, and transitions to community based living environment with the Bureau of Transitional Services.

## Clinical Services

- Provides clinical oversight and leadership on health care, service supports and behavior programming for the entire Division.
- Monitors the implementation of new legislation and administrative initiatives that impact clinical supports provided to persons with developmental disabilities.
- Establishes educational programming/curriculum for Administrative Rule 116 – Medication Administration Protocol for community providers

## Program Development & Medicaid Administration

- Administers three Home and Community Based Services (HCBS) Waivers that provide services to 22,000 adults and children with developmental disabilities
- Maintains the Illinois Prioritization of Urgency of Need for Services (PUNS) waiting list for Medicaid Waiver services
- Plans for and provides oversight of the Ligas Consent Decree implementation to ensure compliance with the Decree
- Staffs the DDD Regulatory Advisory Board and ensures rule amendments for Division programs and services comply with state statutes and federal guidelines
- Conducts Informal Reviews for appeals of termination, reduction, suspension, and denial of Medicaid Waiver services. Represents the Division at formal hearings held by Administrative Law Judges.
- Receives complaints and other service issue concerns from consumers, family members, providers, and other advocates. Maintains a log of these issues and ensures appropriate action is taken for resolution.
- Reviews and provides Division positions on pending legislation. Represents the Division at legislative committee hearings.
- Enrolls new providers in the Medicaid Program for the three Waivers.
- Conducts post-payment reviews of Medicaid Waiver claims for quality assurance of the financial integrity of the Waivers.
- Serves as Division's liaison for Department-wide strategic planning and outcome measure activities.
- Updates and maintains the Division's website pages.

## Community Reimbursement/Program & Data Support

### Program and Data Support

- Support Central Office Data needs including coordination of hardware and software purchases
- Develops the Division's budget
- Coordinates contracts/grants; ensures deliverables are measurable and tracks payments
- Process central operations travel voucher payments
- Process central operations manual voucher payments
- Collects fiscal and program data

## Community Reimbursement

- Sets reimbursement rates for community programs and long term care settings (ICFs/DD; SNF/PEDs)
- Tracks program status and payment

## ICF/DD Rates Unit

- Maintains rates for ICFs/DD and Developmental Training Providers serving ICF/DD consumers
- Update rates as required based on changes in Provider caseload composition as measures by the IOC (Inspection of Care).
- Process the downsizing of ICFs/DD including downsizing agreements and any required downsizing based rate adjustments
- Process billing for HFS for Developmental Training Billing for ICF/DD consumers.

## CILA Rates Unit

- Maintains the individual authorization information and program authorizations for each individual enrolled in Community Integrated Living Arrangement (CILA); maintains the Day Program authorizations and rates for individuals who receive CILA.
- Maintains Therapy Services authorizations and rates for individuals who receive CILA.
- Maintains and adjusts CILA rates, which may include new rates based on individual changes in ICAP/SIB, ambulatory status, nursing level of need and staff add-on adjustments.
- Transmits all enrollments, terminations and rate information for individuals in CILA to MIS for provider payment.
- Processes individual funding placement packets, issues CILA award letters and CILA turnaround forms.
- Issues recognition of Termination letters for individuals terminating from CILA services.
- Receives, reviews and responds to billing inquiries
- Performs budget and enrollment projections for CILA
- Processes and tracks requests for CILA bed-hold extensions
- Processes and tracks requests for adaptive equipment (53E), assistive technology (53T), minor home modifications (53H), vehicle modifications (53V), CILA add-on requests (53R) and DT (53D)

## Purchase of Service Unit

- Maintains the individual authorization information and program authorizations for each individual enrolled in Purchase of Service (POS) Programs which includes 17D, 19D, 41D, 42D, 61D, 65D, 67D, 68D, 73D, Adult Home Based Support (AHBS), and children (CHBS). Related services for HBS individuals include 55A, 55B, 55C, 55D, 55N, 55P, 55T and 55W.
- Maintains the authorizations for individual enrolled in Day Program only services, such as 31U, 38U, 31A, 36G, 39G, 36U, 39U, 35U, 37U and 31U.

continued on page 13



Phil Milsk

## Legislative Updates - BILL SUMMARY

The following bills of interest have passed both houses of the General Assembly and will be sent to the Governor:

### **SB 1383 - ABLE Accounts**

**Chief Sponsors:**

**Sen. Scott Bennett (D-Champaign)**

**Rep. Kelly Burke (D-Oak Lawn)**

**Summary:** The bill creates the ABLE Account Program in Illinois. An ABLE

account is an account established for the purpose of financing certain qualified expenses of eligible individuals with disabilities under section 529A of the Internal Revenue Code. The State Treasurer will administer the ABLE Account program, and the Treasurer has the authority to issue rules governing the program. ABLE account assets and their income are exempt from State taxation, and disbursements from ABLE accounts are tax exempt and long as they are used for qualified expenses, which are defined by federal law. The extent of federal tax exemption is defined by the Internal Revenue Code.

**Status:** The bill passed both houses on May 31, 2015.

### **HB 3158 - Down Syndrome Information Act**

**Chief Sponsors:**

**Rep. Robyn Gabel (D-Evanston)**

**Sen. Dan Kotowski (D-Park Ridge)**

**Summary:** The bill requires the Department of Public Health to make available up-to-date, evidence-based written information about Down Syndrome that has been reviewed by medical experts and State and national Down Syndrome organizations, including physical, developmental, educational and psychosocial outcomes, life expectancy, clinical course, intellectual and functional development, and treatment options. The information must include contact information regarding first call programs, information clearinghouses, national, State and local Down Syndrome organizations, and other educational and support programs. The information shall be made available to persons who render prenatal care, postnatal care, or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down Syndrome. The information shall also be provided to any person who has received a positive test result for Down Syndrome. The information must be culturally and linguistically appropriate for a woman receiving a positive prenatal diagnosis of Down Syndrome and for the family of a child receiving a postnatal diagnosis of Down Syndrome.

The bill states that a health care provider may, upon receiving a positive test result for Down Syndrome, provide the expectant or new parent with the information provided by the Department of Public Health.

This is a bill the Arc of Illinois worked extensively on with parents of children with Down Syndrome and with State and national Down Syndrome organizations.

**Status:** The bill passed both houses on May 26, 2015.

### **HB 235 - Insurance Coverage for Dental Sedation**

**Chief Sponsors:**

**Rep. Laura Fine (D-Glenview)**

**Sen. Tom Cullerton (D-Villa Park)**

**Summary:** Amends the Illinois Insurance Code regarding mandated insurance coverage for anesthesia provided to persons with disabilities in conjunction with dental care. Currently the mandated coverage applies to children age 6 or under when the covered child is in a hospital or ambulatory surgical treatment center. This bill expands mandatory coverage to children under age 19 who have been diagnosed with an autism spectrum disorder or a developmental disability as defined in the Disability Services Act of 2003 (which includes individuals with intellectual disabilities who meet the definition). The bill also adds coverage for anesthesia provided in a dental office or oral surgeon's office for the newly covered individuals. As a condition of coverage, the covered individual is first required to make 2 visits to a dental care provider.

The Arc of Illinois worked on this legislation with autism advocates and parents, especially Mike Baker, who initiated the bill with Rep. Fine.

**Status:** The bill passed both houses on May 20, 2015. If enacted, it would go into effect on January 1, 2016.

### **HB 1360 - Health and Safety Requirements/ Charter Schools**

**Chief Sponsors:**

**Rep. Robyn Gabel (D-Evanston)**

**Sen. Daniel Biss (D-Evanston)**

**Summary:** This is an initiative of the Chicago Medical-Legal Partnership for Children. It requires Illinois charter schools to comply with all non-curricular health and safety requirements that public schools are required to follow. This includes, for example, home and hospital instruction, self-administration of asthma inhalers, concussion policies and epi-pen administration.

The State Board of Education would be required to post a list of requirements on its web site by September 1, 2015, and revise its list annually. The requirements would be incorporated into local charter school agreements.

**Status:** The bill passed both houses on May 30, 2015. If enacted, it would go into effect immediately.

## What are the functions of the various bureaus/areas within the Division?

continued from page 11

- Maintains the therapy services for individuals who receive POS services listed above. Therapy services include 52P, 52O, 52S, 56U, 57U, 57G, 58U and 58G.
- Calculates, maintains and adjusts all rates for each POS program. Rate adjustments may include new rates based on costs, COLA increases, rate add-on adjustments, and temporary or permanent staff add-on adjustments.
- Processes and tracks individual funding packets, issues award letters, and rate sheets for POS programs; reviews billing and placement inquiries; performs budget projections and enrollment projections by POS programs; processes and tracks requests for POS bed hold extensions; oversees the processing of Respite programs (87D and 89D); maintains the files for all individuals enrolled in POS Programs.

### Quality Management/ Quality Enhancement Section

- Provides division approved Direct Support Person (DSP) and Qualified Support Professional (QSP) curricula for use by community agencies; reviews, for approval, community agency DSP and QSP curricula that differ from division approved curricula; approves QSP and DSP training programs of community providers and reviews community agency DSP training programs at least every two years.

- Develops and trains community agency staff on how to deliver the DSP and QSP curricula, other related topics germane to deliver services and how to add DSPs to the Health Care Worker Registry.
- Reviews and approves credentials of QSPs and behavior intervention therapists to provide services under federal developmental disabilities Medicaid waivers.
- Coordinates the development and delivery of other training related projects and activities to support the work of community agencies and state operated developmental centers.
- Reviews agency plans of action in response to findings and/or recommendations of the Office of the Inspector General.

### Quality Management/ Quality Review Section

- Reviews agency plans of action in response to findings and/or recommendations of the Office of the Inspector General.
- Conducts quality assurance reviews
- Conducts medication administration reviews in community settings
- Conducts focused reviews in response to referrals

## Legislative Updates with Phil Milsk

continued from previous page

### HB 3123 – School Counselors

Chief Sponsors:

Rep. Bob Pritchard (R-Sycamore)

Sen. Pam Althoff (R-McHenry)

**Summary:** The bill clarifies legislation passed in 2014 regarding the services school counselors may provide to students with IEPs.

**Status:** The bill passed both houses on May 26, 2015. If enacted, it would go into effect immediately.



**We're on the Web!**

see us at:

**[www.familysupportnetwork.org](http://www.familysupportnetwork.org)**

## Someone You Should Know!

**Faye Manaster M.Ed.** has a combination of decades of health-related professional experience plus parenting experience that have made her uniquely qualified to serve as The Arc of Illinois Family to Family Health Information Center Project Director, a position she has held since 2006.

She has developed and nurtured a wide-ranging network of productive relationships with family groups, health and disability organizations on the local, state, national and international levels. These include Family Voices, Family Matters, the Illinois Medical Home Project, Illinois Newborn Hearing Screening Advisory Board, Illinois Maternal and Child Health Expert Panel, Health and Disability Advocates, Health and Medicine Policy Research Group, Maternal Child Health Leadership Conference and the Illinois Chapter, American Academy of Pediatrics, Committee on Children with Disabilities.

Prior to joining The Arc of Illinois, her professional experience has included the fields of special education, family support, early intervention, and maternal and child health. She has held leadership positions at one of Illinois' Parent Training and Information Centers, a large regional Early Intervention Local Coordinating Council, and the University Of Illinois School Of Public Health.



Maya and Faye

Between 1984 and 2006, she served as a consultant to state and federally funded programs/projects and non-profit agencies serving children and youth with special health care needs and their families.

Ms. Manaster is fluent in Sign Language and Hebrew. She has a 33-year-old daughter, Maya, who is deaf/blind and has cerebral palsy and other special health needs as the result of extreme prematurity.

Maya is a high school graduate who communicates via reading/writing Braille and tactile sign language. She is an avid reader, loves to travel and hopes to pursue a career in dog massage and Reiki. A single parent, Ms. Manaster and her daughter both reside in north suburban Cook County. Maya now lives in a CILA home in her own community. Prior to Maya's birth, Faye was a special education teacher and guidance counselor in Israel and in Chicago.

Ms. Manaster can be reached at [familytofamily@thearcofil.org](mailto:familytofamily@thearcofil.org), and [www.familyvoicesillinois.org](http://www.familyvoicesillinois.org).

### *Save the Dates!*

**October 1, 2015**  
**Living With Autism**  
*conference at the Hilton in Lisle*

**October 20, 2015**  
**Update on Health Care Reform  
for Children and Adults with  
Special Needs**  
*at the Doubletree Hotel in Alsip*

**January 26, 2016**  
**14th Annual QIDP Leadership Conference**  
*at the Doubletree Hotel in Alsip*

**February 4-5, 2016**  
**The Arc of Illinois Leadership Conference**  
*at the Hilton Hotel in Lisle*

**April 20-21, 2016**  
**The Arc of Illinois 66th Annual Convention**  
*at the Hilton Hotel in Lisle*

# More Know Your Options & FSN Outreach Events 2015!



## Legislative Coffee

March 25, 2015  
Springfield, IL



Rep. McAuliffe, Rep. Kifowit, Rep. Moylan, Kim and Katherine



Chuy and Gary



Dir. Romano, Katherine, Tony, Rep. Kifowit and Rep. McAuliffe

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what we can't do alone!*

Shirley A. Perez, Executive Director  
Cynthia Justice, Administrative Assistant  
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The mission of the Family Support Network is to unify individuals with disabilities and their families to advocate for funding, services and community resources that strengthen and support the individual and the family directly by responding to their individual needs and empowering them to live in their own homes. The Family Support Network further seeks to ensure the continuation of all individual supports throughout the life span of the individual.