

# DayOneNetwork

Child and Family Connections #4 and Community Access Programs

*finding a way for people with disabilities*

## Who Is Taking Care of You?

Fall 2011



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When a parent learns their child has a developmental delay or disability, the stressors that accompany this news are inevitable. Because children with special needs often react badly to stress, it is important for parents to remain calm while staring down the future bumpy road. So how do parents of special needs children manage to care for themselves when they are using so much energy to care for their loved one?

The first recommendation is to find someone to talk to. It is important to vent your feelings to someone you trust and understands the myriad of feelings that ebb and flow. Getting your feelings 'out' will help deal with the feelings coming in. Next, find a support group of parents who are facing the same issues that you are. There is strength in numbers and other parent advocates will understand the nuances of having a child with a special need. Third, unplug from the world. Recent research has shown that there is a 'Facebook' depression caused by stress from reading other's posts. In addition, with instant email, twitter, and other social networking tools on smartphones, there is no escape. So, put the phone down and take a break. And finally, ask for help! Do not be afraid to reach out to your DayOne advocate, your doctors, providers, friends and family. There are so many resources that will help you and here are just a few:

\*Mothers United for Moral Support (MUMS) 630-554-8989

\*You Are Not Alone (Y.A.N.A.) 630-879-0076

\*National Association for Downs Syndrome (NADS) 630-325-9112

\*Autism Speaks 888-288-4926

\*Gigi's Playhouse 847-885-7529



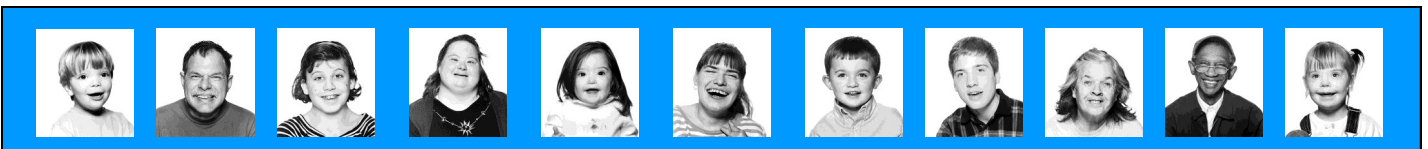
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dayone



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Adrienne LeFevre

**Office Coordinator:**

Cheryl Warren

**Support Staff:**

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Christine Olsen

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Brian Carr-Lisle

Matt Miller-Yorkville

*Interested in serving DayOne as a Board Member? Please contact Joyce Helander to learn about the criteria. We would love to have you!*

## From the Director's Desk

In the summer issue of the DayOneNetwork newsletter, the budget for FY12 was noted as going in the wrong direction. It still is. Advocates for the developmentally disabled (DD) need to be applauded in holding several efforts to cut disability funding in the community in FY12 particularly in these trying economic times. It is positive in that the proposed cut of 6% in Medicaid rates across the board in the community has struck down. Of course, this elimination of the cut comes at a price and this means that payment delays will be further extended in the coming year as well as the possibility of no approval allowing the provider system expedited payment process.

The future of some services such as epilepsy grants, dental grants, and respite services-in-home, voucher, and group as well as Family Assistance program remain in question for continuation. All of this continues to point to the wrong direction in current thinking that supports the strengthening of community

based services over maintaining ongoing institutional care where the State is showing increases in state institutional budgets in FY12. The State institutional employees are to receive the first of their 8.25% wage increase that was slated to occur between January 2011 and February 2012.

Most providers see the state employees wage increases at their expense as the community-based agencies have not been able to offer staff salary increases. Furthermore, cuts to vital programs are such losses of critical supportive services to those families with special needs children. These families need "respite" to help them maintain their child in the home. The cost per person in a state operated facility is exorbitant at \$192,000 per year while the average cost for a small group home is about \$60,000. Cost of care in Intermediate Care Facilities for DD (ICF/DD) is about \$400 million supporting 7,000 individuals while \$600 million serving 45,000 individuals in community services clearly is the most sensible and cost effective services. Illinois,



unfortunately, ranks 47<sup>th</sup> in community spending for children and adults with DD and 51<sup>st</sup> in the number of small group homes for children and adults with DD.

What's more, community based services for DD have not received an increase in the past four years. Plus, there are over 21,000 persons statewide with DD on the State's waiting list for community services.

Much work is still ahead of us. It is time for the State to seriously rebalance the DD system in Illinois and be steadfast in moving the DD system to be a quality community based approach and strive to close all state institutions system within the next five years. This action will redirect those resources into the community. And, if we concurrently end the wage disparity between state employees and community-based organizations, quality staffing and programs will be enhanced not compromised.

## Welcome New Board Members

Matthew D. Miller, Vice President of St. Charles Bank and Trust, has been a board member of DayOneNetwork since June of 2011. In addition to working closely with DayOneNetwork, he is actively involved in a number of other non-profits in the Fox Valley area.

Matt has worked in the banking industry for over 13 years in commercial banking and sales management. He earned a Bachelors of Science from Rockford College and a Master of Business Administration from Aurora University.



Matt D. Miller



Andy Crance

Andy Crance, General Manager for the Gordon Flesch Company, has served on the Board of Day One Network since November 2010, except for a brief time in 2009. Andy has also served as a Board member for the Geneva Community Chest for 3 years prior.

Andy, his wife Kim and his two daughters Brandi and Alyssa, reside in South Elgin. Andy has a 4-year-old grandson, Lukas, who also resides with him. Lukas is a special needs child and the driving force for Andy's passion to be a part of the Day One Network family and provide superior service to all those that are in need in our community.

## Our Gracious Supporters (June – November)

The following foundations, grants, corporations, local organizations, and individuals have graciously donated funds for various programs or for operating expenses. Thank you for your generosity!

**Foundations**

-Kane County Riverboat  
-Alfred Bersted Foundation  
-Community Foundation of Fox Valley

**Community Grants**

-Geneva Community Chest

-St. Charles 708 Board  
-INC Board  
-United Way of Central Kane County  
-Kendall County Mental Health

**Corporations**

-All State Giving Campaign  
-Argosy University

-AT&T Employee Giving Campaign  
-Waubonsee Community College

**Local Organizations**

-Bethany Lutheran Church  
-Batavia Mothers Club

## DayOneNetwork's Report Card

Every fiscal year, DayOneNetwork strives to meet the highest standards in addressing the needs of our clients. We are proud to highlight our accomplishments this last fiscal year:

- 99+%** of the children and adults with special needs and their families served report satisfaction with DayOne services.
- 100%** of children and adults determined ineligible for DayOne services were referred to appropriate organizations based on their stated needs.
- 44** events either sponsored by DayOne or actively marketed to educate clients/families on key topics, i.e., futures planning, autism, transitional planning and legislative forum.
- 100%** of infants exiting/transitioning from CFC services and of special education students (18 to 21 years) exiting/transitioning from the public school system received a written packet of information and were educated about the process and contact resources for additional assistance.
- 100%** of infants and toddlers received a written Individual Family Service Plan (IFSP) written in 45 days after referral. Average number of days from referral to IFSP are no more than 29 days.
- 98%** of Early Intervention and Community Access calls for service are returned promptly not exceeding 48 hours.
- 100%** of individuals in "crisis" received "immediate response" once DayOne was notified of the crisis situation.

## Liagas Court Update

The Liagas Court Decree implementation plan was finalized on September 30, 2011. Details will be shared as they are shared with us. Please see the ARC if Illinois website for a copy of the press release. [www.thearcofil.org](http://www.thearcofil.org)



To Make A Donation To DayOneNetwork:

ONLINE:

- Click on 'Support Us'
- Then click on 'Click For Online Donation'

MAIL:

- Use the envelope provided in this newsletter



UPCOMING EVENTS:

- *GALA: March 19, 2012*
- *GOLF: June 4, 2012*

**CAS STAFF:**

- Lisa Jacino
- Amanda Monahan
- Amy Kaiser
- Angela Churney
- Autumn Todd
- Cathy Legaspi
- Cheryl Mesikano
- Jamie Wollwert
- Jazmine Thomas
- Jennifer Johnson
- Kim Franke
- Leslie Hart
- Lisa Thompson
- Megan Kaleta
- Melissa Claus
- Renee DeCamp
- Ryan Tejero

## Community Access Corner

Happy Fall! Hope everyone is having fun and being safe.

The FY2012 budget has been secured for the first quarter of the fiscal year. There appears to be no cuts to DD services at this time, however, that could change for the other three quarters of the year. It is asked that you to keep up to date on the budget talks and call your local politicians for support against any cuts that would affect the already limited Department of Human Services/ Developmental Disabilities' funding.

Illinois Department of Health and Family Services (formerly Dept. of Public Aid) has begun implementing the State's first integrated healthcare program which includes persons with disabilities as well as seniors who receive benefits from Medicaid. This is a pilot program that covers the suburban area including Kane County. The State expects this healthcare program for eligible Medicaid recipients will improve health outcomes and increase quality of life along with saving money. All entities involved in the care of these individuals will work together to coordinate a consumer driven health care

plan. Participants in the Integrated Care Program will have the choice of two plans. The State has contracted with Aetna Better Health and Illini Care as the two entities that will serve and implement the integrated healthcare. Please note that a participant must choose Aetna or Illini Care or one will be chosen for them. The State has set up a Client Enrollment Broker Unit which will be responsible for providing unbiased education of the plans and assisting the individuals who are eligible for enrollment. Those who are eligible for enrollment can complete the process by phone, online, through an enrollment facilitator, or with the assistance of a Community Helper. For more detailed information, please visit [www.illinoiscebICP.com](http://www.illinoiscebICP.com).

As always, it seems necessary to emphasize that the PUNS is not just a data base, it is the entry to services. A person who needs state funded DD services must be on the PUNS to access services. It is recommended that you keep up to date with this issue by visiting the DHS website ([www.dhs.state.il.us](http://www.dhs.state.il.us)) and/or

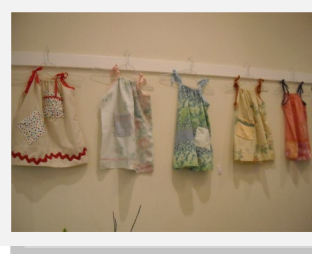
The ARC of Illinois website ([www.thearcofil.org](http://www.thearcofil.org)).

**For anyone interested in additional information on the PUNS or are interested in enrolling in the data base please call 630-879-2277 or your assigned service coordinator.**

Many advocacy groups and individuals continue to work through their legislators and other politically contacted groups to bring awareness to all communities the desperate need for the state of Illinois to increase their funding sources to those individuals who meet the DD. Advocate Network meets on the second Thursday of each month at DayOne and on a Saturday each quarter as well. Fox Valley Special Rec Association, DayOne and AID are working together to come up with solutions to the limited day options families have for their members over the age of 22 through collaboration, brainstorming sessions and educational opportunities for families.

**For everyone that needs additional information on the Advocates Network please contact Gina Richter at [ginar30@sbcglobal.net](mailto:ginar30@sbcglobal.net).**

**\*\*Congratulations to the Community Access staff for receiving a 98.7% at the annual unannounced survey that was conducted October 11-13!!! \*\***



## Shirts for Shorts

When I learned that my friend's church was doing a sewing project to benefit children in Haiti, I knew I wanted to be a part of it. When I found out that they were making dresses out of pillow cases and shorts out of T-shirts, I thought of the left over shirts at DayOne from previous years fundraising events. Joyce, our executive director, agreed that donating the shirts to this great cause made perfect sense. We were able to supply the group with 40 T-shirts that will be used to make 80 pairs of shorts. This project is spearheaded by Doris Frame who will be traveling to Jacmel, Haiti in July to visit the orphanage and take the dresses and shorts to the children. Various groups work on the items throughout the year. If you would like to know how you can help, even if you don't sew, email or call Doris at [dresses4haiti@gmail.com](mailto:dresses4haiti@gmail.com) , 630-406-8474.

Thank you, Gayle Bridger, LCSW

## Child and Family Connections Corner

The EI Monitoring Program ensures that state and federal regulations regarding the delivery of EI services to infants and toddlers under the age of three are met. These areas include the provision of direct services, billing and documentation, service delivery and compliance of statewide Child and Family Connections (CFC) offices and credentialed/enrolled service providers. They also assist families, CFC offices and EI service providers to address issues and resolve conflicts, and safeguard the rights of families to receive appropriate services and supports. This year Child and Family Connection #4 (CFC 4) underwent monitoring in late June. Monitoring's focus was different this year than in the past years. This year's monitoring focused on three sections: Section 1 focused on intake and eligibility, Section 2, focused on 6 month and annual reviews and Section 3 focused on transition and exit info.

Fifty seven closed files were selected for this year's monitoring. After two and half days of intense file reviewing CFC 4 emerged with 97% compliance! Thanks CFC staff for their continued hard work and dedication to their families and the EI system.

In addition, the Department of Human Services/Bureau of Early Intervention (DHS/EI), in accordance with the Individuals with Disabilities Education Act (IDEA), is required to make "Determinations" on the performance of Early Intervention Programs also known as the Child and Family Connection Programs. Determinations are made on an annual basis under the categories:

- (1) Meets Requirements,
- (2) Needs Assistance
- (3) Needs Intervention,
- (4) Needs Substantial Intervention.

Once again, this year CFC 4 received a Determinations of Meets Requirements!

Congratulations and thank you to all CFC 4 staff for their continued hard work and dedication to our families.

Thank you to Batavia Mother's Club which donated \$500 to our Local Interagency Counsel (LIC) here at DayOne. One of the LIC is responsibilities is to promote community awareness about Early Intervention and child development. This donation will enable us to purchase child development materials to hand out at community fairs to help educate families on what skills to encourage with their children.



Lead Service Coordinator Jen Cruz and her husband Pedro welcomed their newest addition, baby boy, Elias Cruz on April 29, 2011. Elias and mom are doing great, congratulations Jen and Pedro!!!!

### CFC STAFF:

Ellana Mavromatis  
Aimee Pfister  
Alana Tosheff  
Amber Jenks  
Amy VanRoekel  
Donna Moore  
Gayle Bridger  
India Washington  
Janice Hopperton  
Jen Hochberg  
Jessica Wilharm  
Lisa Steenson  
Liz Schaeffer  
Lynn O'Toole  
Mandy Zweifel-Hughes  
Megan Mack  
Meghan Croson  
Nancy Clifton  
Nicole Kerr  
Patty Schuler  
Sandi Hix  
Sara Gonzalez  
Shawn Milam  
Stephanie Perry  
Susan Bartelson  
Susie Hulse

## Physical Activity Tips

### **Tips for babies include:**

- plan tummy time with safe, colorful toys
- spend time on the floor with baby during tummy time
- remove infant from the carry seat to allow stretch time
- place infant in safe place where they can learn to pull themselves up
- limit time in molded plastic play stations

### **Tips for toddlers include:**

- go to the park for play time
- give larger boxes for climbing in and out of
- play catch with a large soft ball
- practice walking up and down stairs
- walk to or in the store for shopping

### **Tips for older kids include:**

- take your dog for a walk
- start up a game of kickball
- go to the park with a friend
- help your parents with yard work
- play tag with other kids
- ride your bike to school
- see how many jumping jacks you can do
- race a friend to the end of the block



## Thank You to Run for DayOne Supporters!



This year marked the inaugural merger of DayOne's 5k and Family Walk with the Fox Valley Marathon. Over 2000 runners registered for the event which was held on Sunday, September 18. Runners could choose between a full marathon, a half marathon, a 20 mile, and a kids marathon. The light rain did not slow down the participants who finished

with extremely fast times. Runners, who ran on behalf of DayOne, helped raise almost \$10,000 through their registrations and personal fundraising websites. DayOne was the only charity to provide personal fundraising websites. Runners, for their participation, were provided tech run shirts for race day. It was incredible to see these runners cross the finish line, including Board Member,

Greg Kessler. A special thank you to our sponsors: Kele & Co, Community Therapy Services, Hunter Therapy, CNC Medical Equipment, The Law Offices of Darcy Bielema, Dick Pond Athletics, Feece Oil Co., Geneva Running Outfitters, AID, International Labors Union, Top Pick Athletics, and Animal House Veterinary Hospital.



## Save the Date: Gala & Auction

**March 17, 2012** will celebrate DayOneNetwork's annual Gala & Auction. There will be cocktails, dinner, dancing, prizes, and auction items galore! The night is a celebration of our clients' achievements and our staff's dedication to helping each of them reach their goals.

As DayOneNetwork's largest fundraiser of the year, we need everyone's support to make the event a huge success. If you would like to donate an item, please email [alefevre@dayonenetwork.org](mailto:alefevre@dayonenetwork.org).

love for you to attend. Tickets can be purchased online for \$100/per person or \$750 for a table of 10. Please go to [www.dayonenetwork.org](http://www.dayonenetwork.org) for more information.

We are looking for trips, electronics, packages, restaurant gift cards, etc. We would also



## Feeding Relationships

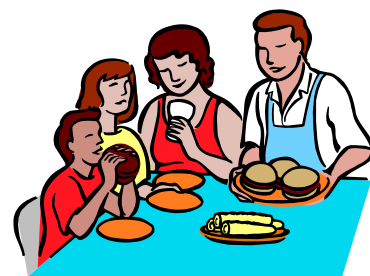
The parent or caregiver is responsible for what, when, and where of feeding, and children are responsible for how much they eat.

Some DO and DO NOT tips:

- DO offer balanced meals and routine snacks
- DO eat around a table with your child
- DO have your infant or baby sit at the table with the family as soon as he/she can sit in a highchair

- DO be pleasant at the table
- DO involve everyone in family talk
- DO offer same nutritious foods for the whole family
- DO introduce new foods to taste more than one time
- DO turn off the TV during mealtimes
- DO put small amounts of each food on your child's plate
- DO have your child ask to be excused before leaving the table

- DO NOT get into food battles
- DO NOT force or bribe your child to eat
- DO NOT comment on the child's eating (good or bad)
- Regular mealtimes give your child a better chance to eat a variety of foods to get the right amount to grow, stay healthy, and keep a healthy weight.
- serve 3 meals and 2 snacks
- serve a variety of healthy foods
- see what works and plan from there



## DayOne Reliance

Historically, persons with disabilities could not transfer their assets to a Special Needs Trust (SNT) and preserve eligibility for needs based government benefits. This changed in 1993 with the advent of the Omnibus Budget Reconciliation Act of 1993 (OBRA '93). This legislation created the second category of special needs trusts, exempt trusts that contain the assets that belong to a SSI or Medicaid recipient. These trusts were codified at 42 U.S.C. §1396p(d)(4)(A), self-settled single trust, and at 42 U.S.C. §1396p(d)(4)(C), self-settled pooled trust.

Sometimes these trusts are referred to as self-settled trusts, first party trusts or (d)(4)(A) payback trusts or (d)(4)(C) pooled payback trusts. The payback term is important and it serves to differentiate these trusts from the third party or estate planning SNTs. The self-settled trusts, whether single or pooled, share in common that upon the death of the beneficiary, all states that have provided Medicaid funded services must be repaid.

The government struck a deal - in exchange for permitting a Medicaid or SSI recipient to retain eligibility or to enable an individual to accelerate eligibility, the recipient must transfer his countable assets to the self-settled

trust, and agree that upon the recipient's later death, the government is repaid before the balance can be distributed to his/hers. In many cases, the funds in the trust will be used up during the beneficiary's lifetime to provide for care and services not covered by Medicaid so payback becomes a non issue.

The self-settled single special needs trust authorized by 42 USC §1396p(d)(4)(A) enables the SSI or Medicaid recipient to transfer their own assets to the payback trust for their needs, but the recipient must be under age 65. The self-settled single special needs trust can only be established by the beneficiary's parent, grandparent, court or guardian and not by the person with the disability.

In contrast, the pooled self-settled special needs trust pursuant to 42 USC §1396p (d)(4)(C) enables the person with the disability, regardless of age, to transfer his or her own funds to the trust for his or her own needs provided the following requirements are met:

1. The trust is established by a non-profit association;
2. A separate account is maintained for each trust beneficiary, but for purposes of investment and management, the separate accounts are pooled;
3. The person with the disability, as

well as the parent, grandparent, court or guardian, is authorized to sign the joinder agreement to participate in the pooled self-settled special needs trust;

4. To the extent that funds remaining in the beneficiary's account upon his or her death are not retained by the trust, the trustee pays to the State(s) from the remaining account balance an amount equal to the total amount of Medicaid assistance paid.

The beneficiary does not create the special needs trust. Instead, the non-profit agency establishes a master pooled trust approved by Medicaid and SSI and the beneficiary joins the trust by signing a joinder agreement. The Trustee then establishes a separate account for the beneficiary and administers the account as any other special needs trust.

Darcy J. Chamberlin, of Chamberlin Law Group, Oak Brook, Illinois, a full service estate planning and trust administration firm. Ms. Chamberlin received her law degree from Indiana University, Bloomington, Indiana. She regularly teaches courses to attorneys and other professionals on special needs trust drafting and administration.

# DayOneNetwork

*finding a way for people with disabilities*

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## SAVE THE DATES

March 17, 2012: Gala & Auction, Q Center  
June 4, 2012: Golf Outing, Aurora Country Club



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