

# The Family Support Network

5739 W. Martindale Lane, Peoria, IL 61615 309-693-8981 [fsn@familysupportnetwork.org](mailto:fsn@familysupportnetwork.org) [www.familysupportnetwork.org](http://www.familysupportnetwork.org)

## We're BACK!! The FSN and Arc of Illinois Form Alliance for the Future!

For more than fourteen years, the Family Support Network (FSN) has been advocating for home and community-based supports and services for people with disabilities in Illinois. We've made great progress.

Our advocacy efforts have lead to doubled enrollment in the Family Assistance and Home-Based Support Services Programs. We've been educating our policymakers about the kinds of programs and policies that people with disabilities and their families want.

We've lead the way, "saving" the Home-Based program three years ago when it was threatened by state cuts and continued to try to improve it within the waiver rules.

We've worked with the "Do the Right Thing Coalition" to increase and improve so many important programs.

We've published more than 20 newsletters, created an information filled website, and developed an e-mail distribution list of over a thousand.

We've held over 35 One-Day Conferences training advocates about Illinois services and how to work together to improve them. We created and trained the Illinois Family Support Task Force.

We've made sure that families were "at the table" when important decisions were being made that impacted our lives.

We've done all of this with help, support, and funding from the Illinois Council on Developmental Disabilities, the Illinois Division of Developmental Disabilities, the Federal Commission on Developmental Disabilities, and your help through donations and memberships. Big thanks to all of you!

Two years ago, our funding ran out. We've hung on with a wing and a prayer. With sheer stubbornness, we've kept going.

Now the FSN is proud to announce its alliance with The Arc of Illinois, a historic moment in advocacy for people with disabilities in Illinois!



*Arc President Lorraine McCormick, FSN Ex. Director Charlotte Cronin, and Arc Ex. Director Tony Paulauski celebrate at The Arc's Sept. Board meeting.*

We will remain our own corporation with our own not-for-profit status. We will continue the important advocacy work for which we are known. But, we will enjoy the benefits of being allied with an organization with a long, proud history of advocating for people with disabilities and with a stable financial and administrative structure.

The FSN and The Arc have already celebrated great success with new funding from the State of Illinois to support the Family Support Network and the Illinois Life Span Project. This new funding is the direct result of the hard work of Tony Paulauski, Executive Director of The Arc. Thank you, Tony!

Work is already under way. The Family Support Network is making plans for the beginning of "Illinois STARS for the Future", an eight-month training designed to inform and empower self-advocates and family members to be real participants in personal and systems change (pg.7). We are hiring two new advocacy coordinators (pg.2) and the newsletter you are reading is a direct result of that new funding!

The FSN and The Arc of Illinois share very strong common values and have worked together for many, many years with huge success. Together we will be so much more than we would ever be separately.

This is a historic moment, not only for our organizations, but for the disability movement in Illinois. We hope you will join us not only in celebrating this historic alliance, but in our continuing struggle for the quality supports and services that people with disabilities in Illinois need and deserve!



## Illinois LifeSpan Project – Information Online for Families

**Where do you go for information about advocacy resources and services for people with developmental disabilities in Illinois?** Many people contact the Illinois Life Span Project at The Arc of Illinois. Illinois Life Span helps families find out about where to go for supports and services in the State of Illinois. We call it "Illinois Life Span" because we help families with loved ones of any age who have developmental disabilities. From the early intervention system and special education advocacy resources through the transition to adult services and beyond, the Illinois Life Span project asks the questions that many families don't know to ask to get the help they need. Families like calling our hotline number, 1-800-588-7002, because of our personalized attention and reliable follow up contact. We want to make sure that the referrals provided meet the needs of the families who call the Illinois Life Span Project.

For people who like to do research on their own, our website [www.illinoislifespan.org](http://www.illinoislifespan.org) offers information on all the service providers funded by the State of Illinois, benefit resources, recreation programs and other opportunities you may not have thought about to

support people with developmental disabilities. The website also has support groups for specific disabilities listed. National, state and local advocacy organizations are posted on the site under "Advocacy Services" and "Links" for people to connect with others who are in similar situations.

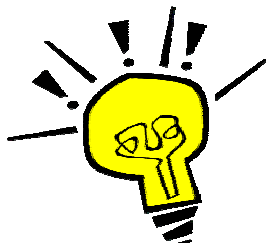
While this website is a very good tool, we are working on a better one! Coming soon, the Illinois Life Span Project will have forums where people can post messages and respond to other posts to share information and resources. These forums will help people share information better than word of mouth, since the words of many mouths will be posted for months to come. The newly enhanced [www.illinoislifespan.org](http://www.illinoislifespan.org) website will have videos of Arc training events, special videos on advocacy and so much more. We have an advocacy toolbox to help people understand resources which might be helpful. We are looking forward to launching the new website in October, 2005. In the meantime, please visit us online or give us a call at: 1-800-588-7002.

By Mike Kaminsky, Illinois Life Span Project Director

## Job Opportunity! Enthusiastic Advocate Desired!!

The Family Support Network is creating two new positions; "Chicagoland and Downstate Advocacy Coordinators". These positions are designed to be part-time working about 20 flexible hours a week from home offices.

Applications are now being taken. Both of our new Advocacy Coordinators must be an energetic, creative people committed to the philosophy of Family Support.



He or she must also:

- Have computer skills
- Be a self-motivator
- Be well organized
- Be able to work unsupervised
- Be able to keep confidences
- Be diplomatic

- Be able to listen to others with patience and empathy
- Be able to speak in front of groups
- Be able to contribute written articles to the FSN Newsletter or similar publications

Our Chicagoland Advocacy Coordinator must be fluent in English and Spanish

Resumes may be submitted to the FSN at 5739 W. Martindale Lane, Peoria, IL 61615 or by e-mail at [fsn@familysupportnetwork.org](mailto:fsn@familysupportnetwork.org). A complete job description is available by e-mail or by calling 309-693-8981.



# PUNS - Prioritization of Unmet Need for Services

## Victory and Confusion

**Two years ago, advocates celebrated a historic victory when a bill was passed by the Illinois General Assembly creating a cross-disability database or waiting list for services for people with disabilities in Illinois.**

Now, for the first time, disability advocates can anticipate having real and accurate information about the needs, met and unmet, of people with disabilities in Illinois.

Last November, the State began officially gathering that information for persons with developmental disabilities using a survey tool called the **Prioritization of Urgency of Need for Service (PUNS)**.

The name is an unfortunate acronym because, for us, **PUNS is no joke.**

- PUNS will allow us to have accurate information to use as advocates as we talk to our policymakers.
- PUNS will be the tool the state uses as it decides who will receive services on an individual basis.
- PUNS will be the tool the state uses as new programs and services are being developed.

The PUNS Survey is the result of a year and a half of planning and design by Celia Feinstein of Temple University in Pennsylvania and the Illinois Division of Developmental Disabilities. Ms. Feinstein was brought to Illinois by the Illinois Council on Developmental Disabilities after developing a similar survey in Pennsylvania. **Based on that survey, Pennsylvania increased funding for disability services by \$835 million!** History tells us that this is an important effort!

### **THE PUNS SURVEY IS A FAMILY SUPPORT ISSUE.**

As with any new project, there has been plenty of confusion. Many people perceive the PUNS survey as being **ONLY** for people anticipating the need for residential services. Others perceive the survey as being only for adults.

The survey is for **ANYONE** or the family of anyone anticipating the need for services in the next five years. The person with a disability must have a developmental disability as defined by the Division of Developmental Disabilities.

For families of minor children the need may mean respite or after school care. It may mean access to therapies or equipment or home modifications. Do not think about available services or specific programs; think about what your need is. Think about what you haven't been able to get, either because it doesn't exist or because it is not available to you.

If you do not anticipate having a need in the next five years, the PAS agent is not supposed to complete the survey! So be thoughtful about your needs! This is your chance!

Families which include members with disabilities have a hard time acknowledging their needs. Our need to be self-sufficient and competent is vital. Our need to present ourselves to the world as "normal" is powerful. All we want to do is lead a typical life. We bury our struggles.

**THIS IS NOT THE TIME TO BE PROUD. NOW IS THE TIME FOR YOU TO STEP UP AND BE COUNTED.**

This is the time to think critically about what our loved one with a disability needs to be successful, either in your home or his home in the community.

Your willingness to complete the survey will allow us to advocate for family support programs! Currently just over 6,700 individuals have completed the survey. Demographics lead us to believe that as many as 14,000 could eventually be included in the database.

### **THIS IS HOW TO DO IT.**

**Call your local Pre-Admission Screening (PAS) Agency (ISC Agency). They must fill out the survey for you with your input.** You can identify your PAS agency on the web at <http://www.dhs.state.il.us/OfficeLocator/> or through Illinois Life Span on the web, [www.illinoislifespan.org](http://www.illinoislifespan.org), or by phone, 800-588-7002. We have also included a list in this newsletter.

Your PAS agency representative will make an appointment to meet with you, probably in your home, or possibly in their office.

The process of filling out the form involves a face-to-face conversation between the PAS agent and the person with a disability, a family member or a guardian, and any other person the individual with a

disability wishes to include. The survey represents the combined perception of all these parties.

**The PUNS survey must be updated on an annual basis.**

At twelve months, a notice will be issued to all parties of the need to update the form. If not updated, an additional warning will be submitted of the intent to close the PUNS record.

**Some people report being told that they don't qualify or that they're not eligible.** Others report being told that if they don't have a need within five years that they don't need to complete the PUNS. Everybody with a developmental disability who anticipates a need within the next five years should complete the PUNS form. Think critically about your needs. Even if it is "just" respite or "just" after school supports, or "just" transportation.

If you are not satisfied with the survey, feel it has been filled out inadequately or if you feel you have been inaccurately turned down in your request to fill out the survey, you should contact your DHS Network Facilitator at 217-524-2521 or 312-814-2735. Please also contact Mike Kaminsky at the Life Span Project at 800-588-7002. We are trying to understand how well things are going and Mike is tracking questions and concerns.

**Also, please remember that inclusion in the database does not assume eligibility for services or guarantee the receipt of services.**

**WHAT DOES THE FORM LOOK LIKE?**

**The PUNS form first categorizes need by three levels of urgency.**

- Emergency: the individual or caregiver needs support immediately;
- Critical: the individual or caregiver needs support within one year;
- Planning: the individual or caregiver needs support within 1-5 years or their caregiver is aged 60+.

**Then it asks you to identify supports and services you or your loved one with a disability need or will need in the future.** Even if you are doing well now, you need to think about what you need to continue doing well! Our families should not have to become dysfunctional to access help!

Think carefully about the choices being presented. Most will be obvious.

**The PUNS Survey is a new and exciting opportunity for Illinois advocates.** But it is frustrating. As with any new project we are learning. Some question if the PUNS survey is asking the questions we want to answer. Do we really have the opportunity to share our needs? Others wonder if we shouldn't be asking for information for more than five years out. Maybe. Probably. As this process goes forward we will have opportunities to ask for changes to the survey.

But, we must step up and use it to understand it! **Please take this opportunity to contact your PAS/ISC Agency and ask for an appointment today!**

---

## **PUNS and Stipends for Families of Minor Children with Disabilities**

---

The Division of Developmental Disabilities has agreed to designate \$350,000 for one-time stipends to adults and children with developmental disabilities. The Division will identify potential applicants from the PUNS database in starting in October. To be eligible for an application you must have completed the PUNS survey by September 30<sup>th</sup>.

The Division anticipates approximately 140 stipends averaging \$2,500 will be issued to meet one-time needs. Individuals, who are currently receiving little or no services from the Department, will be selected on a random basis from the PUNS database and mailed applications. Attention will be given to geographic distribution. The two main priorities for the stipends are goods and services that improve the independence, productivity, and community integration of the person with a disability; and goods and services that increase the stability of the family unit and assist the family in supporting the person with a disability in the family home.

Advocates are hopeful that more funding will become available in the near future, so even if you have not or cannot fill out the PUNS survey by September 30<sup>th</sup>, sign up as soon as you can! It's important!

## DD Definition For Eligibility of Services

*Following is the definition of developmental disabilities used by DHS. You must meet this definition for state-funded services and to be included in the PUNS database.*

A person is determined to have a developmental disability if the person has Mental Retardation or a Related Condition.

Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 22 years. Significantly subaverage is defined as an IQ of 70 or below.

A related condition refers means the individual has a severe, chronic disability that meets all of the following conditions: It is attributable to Cerebral Palsy or epilepsy or any other condition other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with mental retardation and requires treatment or services similar to those required for these persons.

It is manifested before the person reaches age 22. It is likely to continue indefinitely. It results in substantial functional limitations in three or more of the following areas of major life activity: self-care, understanding and use of language, learning, mobility, self-direction, capacity for independent living.

## Just What Are Pre-Admission Screening Agencies and What Is It They Do?

Pre-Admission Screening (PAS) is really a service that is provided by **Independent Service Coordination (ISC) Agencies**. Eighteen such agencies are located around the state for easy access. You do not get to choose which agency you want to use. You must use the one in your geographic area. A list is provided below. You can also locate your Case Coordination Agency at [www.dhs.state.il.us/OfficeLocator/](http://www.dhs.state.il.us/OfficeLocator/) or through Illinois Life Span, [www.illinoislifespans.org](http://www.illinoislifespans.org) or 800-588-7002. A list is also provided below.

Pre-Admission Screening is a process through which eligibility for certain state-funded services is determined. Independent Service Coordination Agencies can help connect individuals with disabilities to services for which they have been determined eligible. They can also connect you to other helpful services.

Independent Service Coordination Agencies are the backbone of the service system as they provide choices and options to people and their families as they access the maze of services.

## Service Coordination Agencies

Options & Advocacy of McHenry Country	815-477-4720
Pact, Inc, Lombard	800-637-7181
Suburban Access, Homewood	708-799-9190
Service, Inc., Joliet	815-741-0800
DayOneNetwork, Batavia	630-879-2277
Community Service Options, Chicago	773-884-1000
Community Alternatives Unlimited, Chicago	773-867-4000
Access Services Northern IL, Loves Park	815-282-8824
Community Service Options, Moline	309-278-0022
Western IL Service Coordination, Macomb	309-833-1621
Central IL Service Access, Pekin	309-527-7202
Livingston Co. 708 Board, Pontiac	815-844-7708
Champaign Co. Regional Planning, Urbana	217-328-3313
D.D. Service Metro East, Belleville	618-236-7957
West Central Service Coordination, Pittsfield	217-285-5227
Prairieland Service Coordination, Decatur	217-864-0494
Great River Service Coordination, Jacksonville	217-243-2330
Southern IL Case Coordination, Centralia	800-828-7422

With Great Thanks  
To Our New Partner



# Illinois Stars for the Future

## Advocating for the Futures of People with Disabilities in Illinois!!



### FSN Announces New Training Initiative!!

The Family Support Network is proud and excited to announce a series of trainings designed to empower people with disabilities and their family members to become confident, effective advocates for their futures in their local communities, statewide, and nationally.

We know that the only people truly qualified to change the systems that effect us is "us," people with disabilities and the families of people with disabilities.

Across an eight month period, participants will be trained on current disability issues, technology, and best practices. They will become familiar with the legislative process and how to work with policy-makers at every level. Participants are expected to attend ALL eight sessions

Our training will be free to successful applicants and a \$50 stipend will be provided to each participant for each session attended to help offset travel expenses.

The Family Support Network is especially interested in empowering inexperienced advocates with a wide variety of disabilities and ethnic backgrounds wishing to grow their skills.

Every year the trainings will concentrate on a different part of the state. This year, the Family Support Network is seeking fifteen individuals from the area defined as the Central Network by the Illinois DHS Division of Developmental Disabilities. For the class of 2005/2006, the Family Support Network is seeking out applicants from Adams, Brown, Calhoun, Cass, Christian, Coles, Clark, Cumberland, DeWitt, Douglas, Edgar, Effingham, Green, Hancock, Jersey, Logan, Macon, Macoupin, Mason, Menard, Pike, Montgomery, Morgan, Moultrie, Sangamon, Schuyler, Shelby, or Scott Counties.

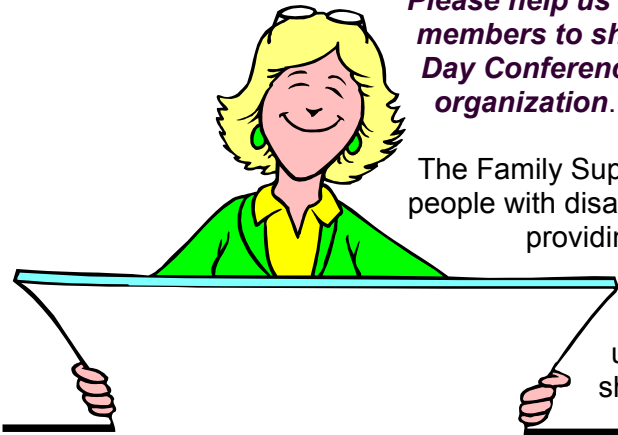
Meetings are tentatively scheduled from 9:30 to 4:30 Saturdays on Nov. 5<sup>th</sup>, Dec. 10<sup>th</sup>, Jan. 14<sup>th</sup>, Feb. 18<sup>th</sup>, March 18<sup>th</sup>, Thursdays on April 13<sup>th</sup> and May 18<sup>th</sup>, and again on Saturday June 17<sup>th</sup>.

If you are interested in being an Illinois STAR for the Future Class of 2006, the complete brochure and application can be accessed online at <http://www.familysupportnetwork.org/2005ArcFSNAAdvocacyTrainingBrochure.pdf>.

## Please Join Us! We Need Each Other!

## Help Us Share the Family Support Message! Host a Saturday One-Day Conference for the FSN!!

*Please help us reach out to people with disabilities and their family members to share information and resources by hosting a Saturday One-Day Conferences with the Family Support Network for your group or organization.*



The Family Support Network has made a commitment to organize and energize people with disabilities and their families around this state. We can do this by providing information and education in as many settings as we can, in as plain language as we can. We call it "mom-speak".

People with disabilities and their families need to have an understanding of current issues and feel they have the skills to share their stories. That is our goal.

We are once again hosting our Saturday "One-Day Conferences" all around the state. We are organizing now for this coming Winter and Spring (2005-2006).

***Can you or a group you are affiliated with help us with a Conference your area?***

**This is the help we need:**

1. Distributing invitational brochures to everyone and every group you know. We would like for you to aggressively advertise the conference to your group's membership and other organizations in your area. The FSN will create and provide the brochures to you. We will mail them to the appropriate geographic area from our database.
2. Finding a site... We need your help finding a place to hold the conference. We usually easily find free sites in settings such as churches, libraries, park district spaces, or agencies. Plan for a space that will hold up to 100 people at tables. Attendance is most often around 30 to 50, but sometimes much more!
3. Inviting one or more legislators for an hour or so in the afternoon. We will help you with this.
4. Providing coffee in the morning and a light lunch in the afternoon.

A typical One-Day Conference is on a Saturday, starts with registration at 9:00 a.m., and ends at about 3:00 p.m. The morning includes talking about our needs, how we got to where we are, the shape of services today, and what we would like them to look like in the future. In the afternoon, we talk about the ins and outs of connecting with your policymaker, do some role playing, and have an invited legislator come to talk with us about how important it is for us to share information with him/her and how he/she best receives that information. We also spend time sharing our stories with the legislators.

**These Conferences are important. People with disabilities and families must be united in telling our stories if we want to be sure the services we need are available. Please Help!!**

***Remember, "We can grumble and groan. We can shake our fists at the sky and bemoan the priorities of the State of Illinois. But, if we don't take time to tell our stories, who do we have to blame? Only ourselves."***

**For more information contact:**

The Family Support Network of Illinois, 5739 West Martindale Lane, Peoria, IL 61615  
309-693-8981 or [fsn@familysupportnetwork.org](mailto:fsn@familysupportnetwork.org).

**Family Support Network**

- **Would you or your organization be interested in hosting a FSN One-Day Conference?**

Please contact the FSN at 309-693-8981 or [fsn@familysupportnetwork.org](mailto:fsn@familysupportnetwork.org).

**The Arc of Illinois**

- **October 17, 2005 – Michael Smull, "Using Person-Centered Thinking To Develop Person-Centered Plans"**  
Wyndham, Itasca, IL
- **October 27 & November 30, 2005 – Brian Rubin, J.D., "Future Planning"**  
October 27 – Masonic Lodge, Watseka, IL & November 30 – 1<sup>st</sup> United Methodist Church, LaGrange, IL
- **November 9, 2005 – Orieda Horn Anderson & Linda Van Dyke, "Sexuality/Spirituality and Persons with Developmental Disabilities"**, Holiday Inn Convention Center, Tinley Park, IL
- **January 6, 2006 - Theresa Varnet, J.D., "Legal & Future Care Planning"**  
Hosted by Glenkirk, Northbrook, IL
- **January 24, 2006 – "4<sup>th</sup> Annual QMRP Leadership Conference"**  
Doubletree Hotel, Alsip, IL

For more info contact Janet Donahue at The Arc, 708-206-1930 or visit [www.thearcofil.org](http://www.thearcofil.org).

**Heart of Illinois Down Syndrome Association**

- **October 21, 2005 – "Creating Inclusive Schools"- Presented by Doug Fisher, Ph.D., San Diego State University**  
Eureka College, Eureka, IL For more information, contact HOIDSA at 309-712-4852

**StarNet Region IV**

- **October 28-29, 2005 – "Piecing It All Together – How Children’s Mental Health & Mental Illness Affect Family, School, & Community"**  
Four Points Sheraton, Fairview Heights, IL For more information, contact Irene Angelou at 618-463-2152

**Sibling Connections Conference, 2005**

- **October 22, 2005 – Hosted by the RRTCADD at the U of I Chicago**  
Center for Enriched Living, Riverwoods, IL For more information, contact John Kramer at 312-996-7988

**Lewis & Clark Community College – Free Assistive Technology and Transition Fair**

- **October 14, 2005 – Lewis & Clark Community College**  
Lewis & Clark Community College, Godfrey, IL For further information, contact Debra Fitzgibbons at 618-468-4209

**FAMILY SUPPORT NETWORK**  
5739 West Martindale Lane  
Peoria, IL 61615-9669

NON-PROFIT ORG  
U.S. POSTAGE  
PAID  
PEORIA, IL  
PERMIT NO. 800

Return Service Requested

*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.*