

The Family Support Network

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Creating a Waiver for Children The Time is NOW!! We Need YOUR Help!

Breaking news is on the horizon for families of children with disabilities. The important work of the Autism Task Force has produced a ground swell of momentum in the Illinois General Assembly to create a waiver to provide support to families of children with disabilities in Illinois.

In the past the only programs providing support for children with disabilities in their family homes have been the Family Assistance Program, a small program commonly referred to as "72D", and grant funded programs through local service providers.

The Family Assistance Program has had no new funding to enroll families in over 3 years. "72D" supports about 400 families of children with severe behavioral issues. Locally funded programs, typically providing respite services, are far too often non-existent or stretched too thin.

A new children's waiver could include supports such as Applied Behavioral Analysis Therapy, parent education, social skills training, therapies not covered by insurance, environmental modifications to the home, transition services, crisis services, and assistive technology.

We are advocating for the enrollment of 3350 children over a 3-year period (800 the first year, +950 more the second year, +1600 more the third year). Each child would have access to supports and services valued at up to 2.5 times SSI, which equals \$18,090 per child per year. All expenditures would be eligible for federal Medicaid matching, which means the Federal government would reimburse Illinois half of all expenditures.

The moment is now! The Autism Task Force Report has provided the momentum and information we need. It is up to us to work together to bring their work to fruition.

The needs of children with various disabilities are far more alike than different. All families of children with significant disabilities have dramatic stories of need. We must work together to encourage our legislators to create a new children's waiver supporting children with all disabilities.

The Children's Waiver Concept proposed by The Autism Society, The Arc of Illinois, and The Family Support Network can be reviewed at <http://www.thearcofil.org/document.asp?did=450>.

What is a Waiver? Why Is It Important to Us?

Many services for people with developmental disabilities are now being funded with a mix of funding from the State of Illinois and the Federal Government. The state pays for the services and the Feds reimburse 50 cents for every dollar spent. In other words, they each pay half. This is done through what is really a federal insurance program for low-income people called Medicaid. Most people with severe disabilities are low income, so they qualify.

States need to "capture" as much Federal funding as possible to support services. Being able to "capture" these federal dollars is very important and makes states such as Illinois much more willing to create and expand programs and services.

When Medicaid was passed into law in the 1960's it only paid for people to be in hospitals and nursing homes. Eventually Congress realized that hospitals and nursing home were very expensive and many people didn't want or need to be in them. But, they were stuck using them as there were no alternatives. Congress passed a law allowing the Secretary of the U.S. Department of Health and Human Services to "waive" the rules in certain circumstances. States have to design services, make specific application, and get approval to waive the rules within those programs. States and participants then have to live by the rules and guidelines the Feds approved.

"Waivers" allow states to create programs that allow a lot of services in community settings such as group homes, the Home-Based Support Services program, and if we're persistent, a new children's waiver.

The Autism Task Force Report: My Loved One Doesn't Have Autism... So.. Why Do I Care??

The challenges of people with disabilities are more alike than different.

The Autism Task Force, made up of families, professionals and DHS staff, worked for two years to create a report to the Illinois General Assembly on the challenges of raising a family member with Autism in Illinois. The thirty-two page report (<http://www.illinoislifespan.org/publications/document.asp?did=442>) was presented by DHS to the Governor and General Assembly on Sept. 1, 2005. It is an incredibly important milestone for people with Autism and for ALL people with developmental disabilities in Illinois.

Recommendations contained within the report include but are not limited to:

- Creation of a Children's Waiver,
- Supports be available 24 hours a day, 7 days a week, across the lifespan, and in all geographic areas,
- Changes in the current waiver program to allow for maximum use of Federal Medicaid matching dollars,
- An increase in services provided by the waiver to include an array of family friendly services such as respite, parent education, social skills training, therapies not covered by insurance, environmental modifications to the home, transition services, crisis services, assistive technology, and Applied Behavioral Analysis Therapy,
- Greater focus on appropriate assessment strategies, "best practices", transition services, community-based services, and home-based services,
- Family and person centered supports provided along a continuum tailored to individual need and able to adapt to personal or chronological development,
- Mandated insurance coverage for Autism Spectrum Disorder (and similar conditions),
- Establishing outreach, education, and networking efforts as well as greater collaboration and communication among all agencies and service providers to create a seamless system in which

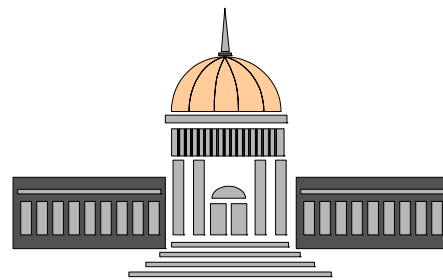
- informed families can make choices and adequately navigate their way,
- Elimination of the IQ requirement for services and focus on "Activities of Daily Living" sometimes referred to as ADLs. Many people with Autism and other disabilities such as Cerebral Palsy have IQs over 70, the current maximum for waiver services. This causes some people with VERY challenging disabilities to "fall through the cracks" of services.

In addition, the report contains sections related to an array of other issues such as education and adult employment. The issues are too vast and complex to summarize here but can be read in detail at the website listed above.

Momentum is building!

Since the presentation of the report at the beginning of September, there have been an unprecedented number of Illinois House and Senate Hearings focusing on its findings. The momentum is very exciting to create a waiver providing services for children with developmental disabilities. With your help this waiver can become a reality!

The report of the Autism Task Force has created a roadmap for change. Please join us in educating our policymakers about its importance for all people with developmental disabilities in Illinois!



LOBBY DAY AT THE CAPITOL

Wednesday, March 22nd

Join Us in the Stratton Cafeteria for Handouts, Help, and Moral Support!!!

8:30am to ???

www.familysupportnetwork.org

We Need Your Help Now!!

Tell your story: Why are these programs important to you? Tell your personal story. Write letters to the Governor, Secretary Adams, Director Johnson and the legislators listed below. A sample letter can be found on our website.

Visit your legislator in his or her home district. Make sure he gets to meet your family member with a disability. We can hook you up with other families in your district. We can also provide you with tips and materials to make sure you're comfortable.

Copy this alert and share it with fellow advocates. We need to speak in a united voice - the more people who know, the louder our voice.

Send us your e-mail address. E-mail allows us to communicate with you immediately and for free! E-mail us at teresa@familysupportnetwork.org.

Check out our website regularly. Our website will be updated with new information regarding these changes and you will be able to download information and handouts. www.familysupportnetwork.org.

Mail Your Letters To:

The Governor, the Secretary of DHS, and the Director of the Dept. of DD:

The Honorable Rod Blagojevich
207 State House
Springfield, IL 62706

"Dear Governor Blagojevich"

Carol L. Adams, Secretary
Department of Human Services
100 S. Grand Ave. East
Springfield, IL 62762

"Dear Secretary Adams"

Jeri Johnson, Director
Department of Human Services
Division of Developmental Disabilities
100 S. Grand Ave., 2nd Floor
Springfield, IL 62762

"Dear Director Johnson"

Your State Legislators:

If you don't know who they are, call us or look up their names and addresses at:
<http://www.elections.state.il.us/DistrictLocator/SelectSearchType.aspx>.

These Key Senators:

The Honorable Emil Jones
President of the Senate,
507 West 111th Street
Chicago, IL 60628

"Dear Senator Jones"

The Honorable Frank Watson
Senate Minority Leader
1355A S. State Rte 127
Greenville, IL 62246

"Dear Senator Watson"



These Key Representatives:

The Honorable Mike Madigan
Speaker of the House
6500 S. Pulaski Rd.
Chicago, IL 60629

"Dear Speaker Madigan"

The Honorable Tom Cross
House Republican Leader
530 W. Lockport St., Ste 204
Plainfield, IL 60544

"Dear Leader Cross"

The Honorable Lee Daniels
Chairperson, Disabilities and Mental
Illness Committee
105 S. York Rd., Ste 550
Elmhurst, IL 60126

"Dear Representative Daniels"

One Family's Story

“My wife is burnt out – we have been doing this for 18 years. She can't keep up with this at the same rate. She lost her career. I lost my career. All of our dreams are just stopped. Everything is stopped.

If we can get a lot of these things taken care of, it will take a lot of the burden off of me to do other things that need to be done. I'm not talking about wants. I'm talking about needs.

Serious business. We're trying to develop their own space by adding on to the house. We're trying to make an apartment for the girls so we can be right here as they adapt to an independent life style.

Dental work, medicines that they have to have... I spend all my money on things like that for them. Insurance does not cover everything. We have very limited resources to tap into to make ends meet at times. My account is drained. When they need things, we're picking up and taking care of it -- but we can't put back in.”

Larry and Pam Bruce are parents to three adult

children: Julian, Paris, and Paige. Unlike their older brother, 18-year-old Paige and Paris still rely on their parents for most of their personal needs. The twin girls were born at 32 weeks with significant respiratory issues diagnosed as Kartagener syndrome.

Both require daily respiratory therapy and take the strongest oral antibiotic prophylactically. In addition to being medically fragile, both have developmental delays and motor issues including fused bones in joints and low muscle tone.

The Bruce's have been trying to find some support to make their home more physically accessible to the girls, increasing their independence. For example, Paris can care for her own needs in the shower, but she can't get in and out because of the physical restrictions of the non-accessible tub. Something as simple as an accessible bathroom would allow Paris the dignity of bathing independently.

The Bruces need support! Let's “Do the Right Thing”.

“Do the Right Thing Coalition" Needs Unaddressed!!

Governor's Proposed Budget Includes No Funding for New or Expanded Services!

On February 15th, Governor Rod Blagojevich announced his proposal for the Illinois budget year beginning July 1, 2006 and ending June 30, 2007, often referred to as the FY 2007 Budget for the year it ends in. Advocates were disappointed to discover that NO NEW FUNDING had been included for new or expanded services for people with developmental disabilities.

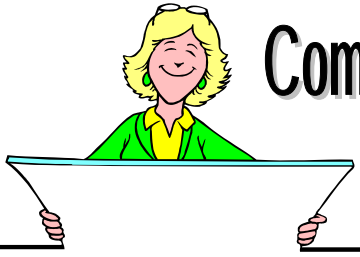
Advocates are asking for increases in funding that would not only allow current services to keep up with the cost of living, but provide new services for people who are currently underserved or not receiving services at all!

Join the “Do the Right Thing” Coalition in asking for "Don't Say No To People with Disabilities and their Families!"

We are asking for enough funding for:

1. 5% Enhancement for Wages & Rates
2. New enrollment of 300 people in Community Integrated Living Arrangements (Group homes and in-home services) Increase Community Supports & Services
3. New enrollment of 400 people in the Home-Based Support Services Program
4. New enrollment of 300 children in the Family Assistance Program
5. And funding to create a new waiver for children with developmental disabilities and/or Autism.

Did you know that the newest PUNS data show 204 people over the age of 80 caring for someone with a developmental disability? Think about it.



Coming Soon to a Location Near You... One-Day Conferences on Support!

The Family Support Network has a tradition of providing One-Day Conferences all around Illinois. With the help of our new advocacy coordinators, Dorelia and Michele, we are now able to reach far and wide to expand our grassroots efforts!

This month we have co-hosted sponsored conferences in Villa Park and Jacksonville. On March 18th, we will be co-hosting a conference with **PACE-Urbana CIL in Urbana**. Plans are also in the works for One-Day Conferences in **Hillside** and **Mt. Vernon**. For details and printable brochures please check out our website at <http://www.familysupportnetwork.org/>.

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 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 our policymakers and an invited legislator.

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!!

Watch for upcoming conferences in places like Mt. Vernon, Melrose Park, Pittsfield, and... hmmm... maybe your town!!

If you would like to sponsor a One-Day Conference in your area, let us know. If you sponsor it, we will come! And families across the state will be empowered to advocate for their own needs!

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."

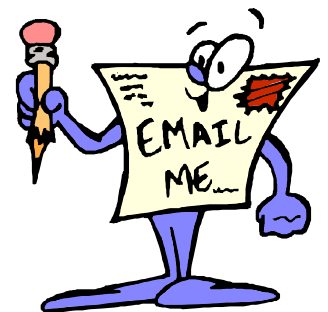
E-mail Send Us Your E-Mail Address!

E-mail is a critical component of our advocacy efforts. Help us update and expand our advocacy efforts by moving into the Information Age! **We need your e-mail addresses** more than ever. The Family Support Network is made up of over 4700 members statewide. But we only have about 1000 in our e-mail lists.

Being able to communicate by e-mail is invaluable. We can contact you quickly and cheaply ... FREE!!

When we organize our advocacy alerts, the first thing we do is compose an e-mail. We can't afford to do a US Post Office mailing whenever we want to. It costs us over \$1100 in postage alone; it's labor intensive and slow.

E-mail also allows us to share information about conferences, legislative action, and more. We promise not to send too much. Send your updated information to **Teresa@familysupportnetwork.org**. Thanks!



FSN Welcomes New Advocacy Coordinators!



The Family Support Network is excited to introduce two new members of our advocacy team! Michele Westmaas of Pittsfield and Dorelia Rivera-Martinez from Melrose Park are our new Advocacy Coordinators.

They have been with us since November and are busy “getting up to speed”. Dorelia and Michele are available to do “One-Day Conferences” in your community, educate on “best practices” to your local advocacy groups, large and small.

They will also be your connection to what is happening on a statewide level with our advocacy efforts!

Above, from left to right, are Michele, Charlotte (FSN Executive Director) and Dorelia enjoying a break from their advocacy efforts in Washington, D.C. this February. They were part of a contingency of eighteen Illinois advocates at the 2006 Disability Policy Seminar co-sponsored by The Arc US, AAMR, AUCD, United Cerebral Palsy and NACDD.

Michele Westmaas, Downstate Coordinator

308 W. Jefferson St., Pittsfield, IL 62363
michele@familysupportnetwork.org
 217-285-2301

Eight years ago, I was a family childcare provider, a teacher, and mother to a delightful kindergarten son. State legislation was my least favorite subject! Now, I am eager to understand the ins and outs of disability policy and the who's who of our legislature in order to be an effective advocate for people with disabilities.

My daughter, Aubrie, was born 8 years ago with CHARGE Syndrome. Through these years of learning about her many challenges and following her CHARGE peers as they reach adulthood and find limited opportunities, I have come to realize the importance of Family Support and advocacy!

Our family was one of the fortunate ones to be selected for the Family Assistance Program shortly after Aubrie's birth. What a blessing! But what a shame that there is not enough funding to adequately support all families in need.

By working together to develop a grassroots network, by informing and empowering all families and persons with disabilities, we can make changes to policies and funding so that all of our needs are met in a way that works for each of our unique families.

I distinctly recall a moment in my home with an advocate who was helping us to navigate the Early Intervention system. I said to him, “I want to be you when I grow up.” Since then, I have taken every opportunity to learn more about *the system* and to encourage and assist others in their struggles.

My family is a part of a large worldwide CHARGE family via the Internet. The invisible support of that family has been invaluable to me as I face the obstacles and challenges on our path through what we affectionately call “CHARGEland”. What has been missing for me is a face-to-face connection with people

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in my geographical world. We need to support and empower one another to make changes here – and now. The ripple effect of changes being made by people across geography will make a difference in the world at large. We are on the cusp of great changes in Illinois. What a remarkable time to be joining the Family Support Network!

Dorelia Rivera-Martinez, Upstate Coordinator

800 Sherman St., Melrose Park, IL 60160

dorelia@familysupportnetwork.org

847-791-2432

Mom, wife, daughter, sister, friend, aunt, U.S. Army veteran, teacher, volunteer and now an advocate for all those with developmental disabilities and their families!

Lots of hats, one person! Born February 24, 1974, to two loving parents, Jose & Estela Rivera, I am blessed with one daughter, Kayla (2), and a wonderful husband, Carlos, a UPS Sales Manager in Oak Brook. I'm also blessed with three brothers, two sisters-in-law as well as two nieces and two nephews.

In the last few years, I've worked in Early Intervention (children from birth to three), an experience that has been highly rewarding and has led me to pursue my Masters in Child Development at the esteemed Erikson Institute in Chicago. In my spare time, I love to read, dance, volunteer, play, learn & TRAVEL!

One grand chapter in my life has been "settling down!" After traveling, military, and volunteering, I'm now married to a magnificent, devout, loyal, supportive man whose patience with "my next big idea" never ceases to amaze me.

Kayla is one of my inspirations for doing all that I do for and with families! I would love for you to meet Kayla at www.carepages.com; her page name is "KaylasWorld"!

Kayla was recently diagnosed with a rare congenital syndrome called NOMID. Often, it's misdiagnosed with lupus or juvenile rheumatoid arthritis. The symptoms are periodic spiking fevers, an intermittent hived rash, joint pain, swelling, and progressive hearing and vision loss.

It's taken up a bit of our lives in the last year or so. She is treated at the National Institutes of Health in D.C., where all of the other 22 diagnosed kids are seen as well! We also travel to Children's Hospital in Pittsburgh for her vision. We know there are so many more children that are misdiagnosed. Kayla is the youngest to have been diagnosed at 15 months.

Of course, we have MANY people to be thankful for in our lives. We wouldn't have gotten this far without them -- our families, our friends, my professors, my advisor, Linda, and Dr. ANDERSON- her pediatrician, the BEST! Between their support and our own advocacy as parents, Kayla is a vibrant, verbal, active, loving, huggable two-year-

The Family Support Network

old! Without them, I wouldn't be sitting here today ready and able to take on this VERY important position as an Advocacy Coordinator with the Family Support Network! I'm grateful for the opportunity to make and impact changes in the lives of children and adults!

**"IF YOU
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FIND ME
AT HOME
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THE THINGS
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Family Support Network of Illinois

- **March 18, 2006 – FSN One-Day Conference,**
Co-hosted by PACE, Inc., 1317 E. Florida Ave, Urbana, IL 61801
- **Would you or your organization be interested in hosting a FSN One-Day Conference?**
Please contact the FSN at 309-693-8981 or teresa@familysupportnetwork.org.

The Arc of Illinois

- **Feb. 25, 2006 – “Special Needs Future Planning”**
Y Log Lodge, 200 Y Blvd., Rockford, IL 61107
- **March 7, 2006 – “The Importance of Belonging”**
Chicago Marriott Southwest, 1200 Burr Ridge Parkway, Burr Ridge, IL 60527
- **March 31, 2006 – “Legal and Future Care Planning for Your Relative With a Developmental Disability”**
Good Shepherd Manor, 4129 North Routes 1 & 17, Momence, IL 60954
- **April 5, 2006 – 56th Annual Arc of Illinois Convention**
Hilton Hotel, 3003 Corporate West Dr., Lisle, IL 60532
- **May 16, 2006 – The 4th Annual Arc of Illinois Expo for People with Disabilities**
Tinley Park Convention Center, 18501 S. Harlem Ave., Tinley Park, IL 60477
For more information on ARC events, contact Janet Donahue at 708-206-1930.

FAMILY SUPPORT NETWORK

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Peoria, IL 61615-9669

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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.