

February 6, 2007
Illinois State Capitol



THERE'S NO PLACE LIKE HOME



THE FAMILY SUPPORT NETWORK



AUTISM
SOCIETY
of ILLINOIS

Connecting and Supporting the Autism Community

*Working to ensure that every child and adult with a disability in Illinois
Can live, love, laugh, learn, grow, and work
In the home of their choice with family and friends.*



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Connecting and Supporting the Autism Community

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No Place Like Home

Families and advocates rally support to promote programs designed to keep adults and children with developmental disabilities in their local communities.

FOR IMMEDIATE RELEASE:

February 6, 2007

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Springfield, Ill. – The Autism Society of Illinois, the Family Support Network and The Arc of Illinois kicked off their statewide campaign today urging the Illinois General Assembly to provide increased funding for services for adults and children with disabilities in Illinois. The organizations are requesting an additional \$52 million investment in new funding to help adults and children who are currently not receiving much needed services. These programs are designed to keep adults and children in their local community and with their families.

The programs in need of additional funding include the Family Assistance program, Home-Based Support Services, Community Integrated Living Arrangements and the Children's Supports Services Waiver.

“We want our children to stay in our home with us but if we are not able to get the supports we need to do that our only option will be to move them into a residential setting for their own safety,” said Christine Woosley a Bloomingdale, Illinois resident with two sons, ages 6 and 3, both with severe autism, who spoke on behalf of keeping her children at home with their families to receive services. “We do not want it to come to that. It would be tragic for us, tragic for our sons, and expensive for the state of Illinois.”

The programs in need of additional funding would provide services to 2,542 children in Illinois under the age of 18 who are in need of services, 444 adults with developmental disabilities who need support to continue to live at home, which is a less expensive setting than residential living, and 250 people who need to transition to living away from their family home.

-more-



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“These programs represent real help for real families and individuals today,” Charlotte Cronin, Executive Director of the Family Support Network, said. “Services are tied to the individual first, not the agency or service provider. They offer individuals and families the opportunity to be flexible and creative, to design the services best suited to their needs.”

Another main focus of this statewide campaign is to generate funding for programs to assist adult Illinoisans with developmental disabilities currently living with parents or caregivers and who need to transition to community living. In Illinois, there are 964 adults with significant disabilities living with a caregiver over the age of 60, 286 of which are living with parents over the age of 80. Sheila Dickson, a self-advocate from Peoria, spoke from experience on what it meant to her life that she was able to move out of her parents’ home and into a local community living arrangement.

“As my parents got older, they worried about where I would live when they couldn’t help me anymore,” said Dickson. “About eight years ago, I was able to move into a group home in Peoria and receive services there. It is my home now.”

The organizations encourage families and individuals with developmental disabilities to contact them at www.autismillinois.org, www.familysupportnetwork.org, www.thearcofil.org or 309-693-8981 to learn more about the services and programs available for people with developmental disabilities.

“We need to help society’s most vulnerable human beings,” said Cronin “And no one knows those challenges of caring for children and adults with developmental disabilities better than their families.”



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There's No Place Like Home!

Press Conference
Capitol Press Room

February 6, 2007
10:00 am

\$52,000,000 New Dollars for NEW SERVICES!

That's NEW SERVICES for 3,126 adults and children currently receiving NO SERVICES!

That's NEW ENROLLMENT for these important programs:

The Family Assistance Program (FAP)

The Home-Based Services Programs (HBSSP)

Community Integrated Living Arrangements (CILA) which provides services to people living in group homes

The New Children's Support Services Waiver

Program	Additional Children and Adults to Be Served	Cost
Family Assistance Program	*535	\$ 4 million
Home-Based Support Services	**444	\$ 8 million
Community Integrated Living Arrangements	***250	\$10 million
Children's Waiver	****2,007	\$30 million
Total	3,126	\$52 million

- * Based on \$623/month or \$7,476/year
- ** Based on current average spending of \$18,000/year
- *** Based on current average spending of \$40,000/year
- **** Based on projected average spending \$18,090/year



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FACT SHEET

52 million will provide NEW enrollment in programs for individuals (adults and children) who **do not** currently receive services. They include a variety of choices such as Community Integrated Living Arrangements, the Family Assistance and Home-Based Support Services Program, and the new Children's Support Services Waiver.

he true cost of to Illinois is \$28,000,000. ALL of these programs (with the exception of the Family Assistance Program) receive 50% Federal Financial Participation through Medicaid.

o one knows the challenges of caring for children or adults with disabilities better than their families. The cost of special care and equipment can be so great it is impossible to make ends meet. It is often difficult to take a loved one out in the community, isolating the individual and the family.

any people with disabilities need constant care and support, placing caregivers under great stress. Caregivers must often give up jobs and careers, placing their families under further stress. Issues that confront families include financial problems, marital stress, missed opportunities, fragmented services, confusing and contradictory information, stigma, isolation, uncertainty, and exclusion from decision-making.

he Family Assistance Program currently provides a monthly stipend of \$623 (one times SSI) a month to families that include minor children with developmental. Taxable family income cannot exceed \$50,000. There has been NO NEW enrollment for this program in FIVE YEARS!

Children's Waiver will allow families that include children with disabilities to access the important supports and services they need to be strong and healthy and to raise their children to be the best that they can be *IN THEIR OWN HOMES*.

he Home-Based Support Services Program provides adults who have severe developmental disabilities with supports and services with a value up to \$1,869 per month.

New residential placement in Illinois is currently only available to individuals with disabilities who are in desperate crisis -- and even then it's often not available.

The Family Assistance and Home-Based Support Services Programs and the new Children's Support Waiver are part of a growing national movement to offer supports and services to individuals with disabilities and their families at home. These programs allow individuals and families to design services and programs that are flexible and fit their own unique needs.



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Speakers

Charlotte Cronin, Parent and Executive Director, The Family Support Network of Illinois

Lorraine McCormick, Parent and Board President, The Arc of Illinois

Christine Woosley, Parent

Miriam Bucio, Parent

Sheila Dickson, Advocate and President, People First of Peoria

Chris Kennedy, Parent and Legislative Liaison, The Autism Society of Illinois



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Good Morning,

I'd like to take this opportunity to welcome all of you today and thank you for coming. My name is Charlotte Cronin and I am the Director of the Family Support Network of Illinois.

I am here because I am Daniel's mom. Daniel is one of thousands of young people with severe disabilities in the state of Illinois.

He is a member of one of the thousands of families struggling to answer these questions:

How can we find the supports and services our children need to grow up to be the best that they can be?

How can we keep our families whole and healthy so that we can be the best that they need us to be?

Will they have the supports they need to have a whole and happy adulthood?

Who will love them and care for them after we are gone?

Our families face these problems:

Fragmented services that are available in some areas and not others.

Services that are stretched so thin they do no one any good.

Programs that fix us after we are broken rather than support us while we are whole.

Families who have members with disabilities face extraordinary stresses. People with disabilities face extraordinary challenges. Exhaustion, isolation, medical expenses, loss of income, marital stress, missed opportunities, fragmented services.

Four programs help answer these questions. They are the Family Assistance and Home-Based Support Services Programs, Community Integrate Living Arrangements, and the soon to be introduced "Children's Support Services Waiver"

These programs represent real help for real families and individuals today. They also represent the best models of how services to individuals with disabilities can and should be delivered. They are consumer driven. Services are tied to the individual first, not the agency or service provider. They offer individuals and families the opportunity to be flexible and creative, to design the services best suited to their needs.

We are here today to ask the Illinois General Assembly to help us by increasing funding to these programs by \$52 million. We believe an increase of that amount will allow the Department of Human Services to increase enrollment by over 3,100 adults and children.

The FSN is made up of almost 5,000 people with disabilities and their loved ones. We are a scrappy bunch - moms and dads trying to advocate for systems change in between loads of wash, meals, meds, and therapies.



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People who have disabilities and people who have children with disabilities are usually emotionally, physically, and often financially exhausted so we are often invisible. We have a hard time going to Springfield.

To the Illinois General Assembly -

Please know that we exist. We look forward to working with you until every family is served.

Please know that we want our families whole and our children at home

Have Heart. Remember families that are struggling.

Have Brains. This program makes economic sense for the State of Illinois.

Have Courage. Do what you know is right. Support an increase in funding for the Family Assistance and Home-Based Support Services Programs.

Parent and Executive Director, The Family Support Network of Illinois, 5739 W. Martindale Lane, Peoria, IL 61615

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Hello,

My name is Sheila Dickson. It is a pleasure to be here. I have CP and when I was nine years old, my parents sent me to a special school in Chicago so I could get some education. When I first went there I thought they were abandoning me. Mother called me every Saturday and the first year I went home one weekend each month and for holidays and the summer. I was so depressed, I didn't try to learn or get involved in much activity.

I was twenty-one when I left school. Mom got me into Parc's training workshop. I got some more education there and learned to do lots of other things. Parc teachers and therapists were great! I joined People First and attended Partners in Policymaking. I made many friends and learned how to be independent and speak up for myself.

I lived with my mom and dad. They made modifications to our house. They put in a special shower and a ramp. They dedicated themselves to helping me.

As my parent's got older, they worried about where I would live when they couldn't help me anymore. About eight years ago, I was able to move into a group home in Peoria and receive services from Parc there. It is my home now.

My dad passed away three years ago and my mom passed just last year. It was really hard and really sad. But, at least I didn't have to move at the same time to a new house with strangers.

In Peoria, I am able to live close to my sisters and visit with them when I want.

Now I am an advocate for other people with disabilities. I worry because there are too many people living with their aging parents. I worry that they don't get to do anything or go anywhere because their parents can't help them do things. I worry that when their parents die, they will have to move into strange houses far from home at the same time they are mourning their parents. And their parents won't be there to explain what they need.

The waiting list has 286 people whose parents are over eighty years old. They are still waiting for services. There are 642 people waiting for services whose parent are over 70 years or older.

I am here today to ask Governor Blagojevich and our state legislators to make enough money available so that people with disabilities can live in their own homes close to their families while their parents are still strong and healthy and can help them move.

Everybody needs to live close to family and friends. People with disabilities are no different. Please help us.

Thank you!

Sheila Dickson
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My name is Miriam Bucio.

My family is from Mexico. I have three children; Ashley 17, Karen 13 and Brian 9. It was very rough being a young mother at the age of 16. It was even tougher to raise a girl with a disability. I never realized how comfortable I had to become with the language of physical and vocational therapy.

Seventeen years have already passed. With my family being so far away, the things were even more difficult. Karen is thirteen. She does not understand her sister Ashley, but helps me out. Ashley is very mischievous and tiring.

I focus much of my time on Ashley. My two children felt cast aside. Karen is now in adolescence. Her behavior disorients me now as it is when Ashley was born.

But now I have a family that has given its unconditional support. I am speaking of Community Support Services. They have changed my situation. To have a child with a disability totally changes your life.

Ashley is a blessing. But it frustrates me to know that in the 2007, there still are not enough resources for persons with disabilities. There is not enough information. There are not enough doctors treating the disabled.

The public does not understand the Syndrome (Najer's Syndrome) that my daughter has. They are not accepting of persons with disabilities. The local public school does not provide sufficient vocational training for future employment. The only option they offer my daughter is cleaning. We can not expect that our children who finish school will only clean.

I should not get frustrated. Instead, I continue the fight, to inform other parents and not keep quiet. I will not let myself be defeated.

The Home-Based Services Program would provide our family with the flexibility to allow Ashley to select her own vocational service provider in the future.

My daughter is not the first one nor will she be the last person with a disability. My hope is that all persons with disabilities will be given an opportunity and the financial supports that an expansion of the Home Based Funding Program would provide to thousands of families of which I represent here.

Thank you.

Miriam Bucio
630-201-5589



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February 6, 2007

My name is Christine Woosley and I live in Bloomingdale, Illinois with my husband Brandon and our two sons, Joshua and Zachary.

I'm here today to talk about my two wonderful and creative children. Joshua is a six-year-old who loves classical music and knows more than many people about Vivaldi, Mozart, and Bach. Three-year-old Zachary is a mover and loves jumping, climbing and playing with Thomas the Tank Engine. They are the joy of my life and everyday I love them more and more.

Things are not always great, though. Both of my children have Autism Spectrum Disorders. What does this mean? For us, it means CONSTANT supervision. Both Zachary and Joshua are flight risks. Zachary will compulsively go out doors, up and through windows, and over fences. Once he's outside he takes off quickly. Zachary is non-verbal. Even if someone finds him he can not tell them his name.

Once we found him outside his second floor window, perched on an outer ledge, laughing, not at all aware of the extreme danger he was in.

He has escaped out the back door and climbed our back fence, when we thought he was playing in his playroom, and was found a few minutes later at the corner of Lake Street and Bloomingdale Road – major roads with 14 lanes of traffic.

Joshua is also prone to escape. We have installed extensive safety features in our home: locks on all the inner and outer doors in our home, bars on windows that the boys favor, and dowels in the runners of our double hung windows to keep them from opening more than 4 inches. All these are currently helping but they are not a long term solution.

Joshua has already broken a door jam trying to get out a locked door in our home. It is likely that eventually one or both boys will learn how take down our window bars, remove the dowels, or become strong enough to open the windows from the bottom up. When that happens we are back to square one. Once again the boys will be in danger.

The stress of the constant and extreme supervision leaves little emotional resources for marriage, friends, other family members, and jobs. Our lives have become more and more isolated.

Finding relief is daunting. We call agency after agency just to hear them say they will put us on a waiting list or that there is nothing they can do for us because there are no funds available.

The Children's Support Services Waiver would be a lifeline for us. Having the ability to get the specific resources the children need – whether it is help on outings, behavior supports in our home, or to use funds to continue making our home a safe place for our children to live – is huge for us.

We want our children to stay in our home with us but if we are not able to get the supports we need to do that our only option will be to move them into a residential setting



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outside of our home for their own safety. We do not want it to come to that. It would be tragic for us, tragic for our sons, and expensive for the state of Illinois.

This is our story but it is also the story of hundreds of other families' stories. Families want to live together, play together, go places together, and have a place in our society. Please, for their sake and the sake of Joshua and Zachary, support the Children's Waiver.

Thank you,
Christine Woosley

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My name is Peggy Kreichgauer. I have a daughter, Brandi Marsh. Brandi will be turning 21 years old and has multiple disabilities. Brandi graduates from Washington Community High School this year. Currently I have been told that there is no guarantee that she will receive funding for day treatment after graduation— something she currently participates in through her high school program. I've also been told that residential services are out of reach for Brandi because she lives in a household that has two healthy parents.

Brandi is watching her peers and learning from them that the next step into life should be for her to have a job and move out on her own, even though Brandi knows placement would be within a group home. Brandi & I have visited some group homes to include her in the decision as to where she would like to live. Brandi also has a boyfriend who currently resides within a group home. They hope to someday live within the same home together.

Including Brandi in this process allows her the freedom to voice her opinion. Brandi has enjoyed being a part of this, but the heartbreaking news will be a timeline as to when this will happen for her. One of her disabilities prevents her from understanding time concepts —later, in a little bit, soon. Not being able to tell her when she gets to move will be a challenge. This is a question Brandi will ask often when she is sitting home with no place to go and nothing to do.

The thought of knowing that she may only get placement after she goes through the tragedy of losing me -- this is not something that any child should have to deal with -- especially our children with disabilities. I have a passion to get the best placement for my daughter now while I am still able to make the right decisions with her and support her in the transition.

Peggy Kreichgauer
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February 6, 2007

Father of 3, one daughter with autism and epilepsy

Difficulties finding support

Meaning of state services for children in the family home

Nationally, 61% of the 4.6 million people in the U.S. receive residential services from their family members. Yet, only 5% of government funding supports these families.¹

And Illinois lags far behind most other states in such services:

- In a recent study, Illinois ranked 48th in providing small community settings, trailing every state except Mississippi and Alabama.²
- In another study by a national organization, Illinois ranked 46th in overall services for individuals with developmental disabilities.³

What this means for families in Illinois

We are families who are asking for better care for our loved ones

As the state moves to provide better access to healthcare and improved education, we hope our families' dire needs will be included.

Christopher Kennedy

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¹ "Family Support Service in the United States," University of Minnesota Research and Training Center on Community Living, Institute on Community Integration (UCEDD), February 2006.
<http://ici.umn.edu/products/prb/171/default.html>

² "The State of the States in Developmental Disabilities 2005," University of Colorado Coleman Institute for Cognitive Disabilities, at pages 19, 30, 57.
<https://www.cu.edu/ColemanInstitute/stateofthestates/index.html>

³ "A Case for Inclusion ~ An Analysis of Medicaid and Americans with Mental Retardation and Developmental Disabilities," Rating of States for Disability Services; United Cerebral Palsy, Year 2006.
http://www.ucp.org/uploads/full_inclusion_state_report.pdf