



empower

Real People, Real Progress

the arc of anchorage: lack of crisis housing impacts people who experience disabilities

In response to Alaska's growing housing crisis and the increasing strain on the state's mental health system, The Arc of Anchorage has embarked on an ambitious renovation plan to create temporary housing for Alaskans facing mental health, behavioral or other emergencies.



The Arc of Anchorage (The Arc) is remodeling an existing building on its campus to provide crisis housing. Without this alternative, costly and unnecessary psychiatric hospitalization is the only available option. The Arc is taking this initiative to alleviate a strain on Alaska's mental

health system and help correct a dangerous situation.

The crisis housing center will provide a safe, comfortable option when a mental health, behavioral or other emergency needs to be addressed, but hospitalization is not required.

Gwen Lee, Executive Director of The Arc of Anchorage said, "We are thrilled the state invested in the remodel of this building. Once completed, it will fulfill two needs; our need to provide crisis housing for the people we serve and our need to ease some of the strain on the Alaska mental health system."

Funding received from the State is not sufficient to cover the full renovation costs, so The Arc of Anchorage is seeking private contributions to support the project.

News reports in Anchorage highlight the serious issues facing the state's only mental hospital, Alaska Psychiatric Institute (API), and the swelling ranks of their elderly patients – Alaska has the fastest growing elderly population in the

celebrate the arc! convention 2010

The Arc@60! Convention 2010 is shaping up to be one of the most exciting gatherings ever setting the pace with a vision of "A Clear Way Forward;" the reveal of The Arc's new brand; the launch of The Arc's National Film Festival with Sprout and workshops by and for self-advocates, including a special presentation of The Arc's Image & Inclusion Award to actors Robin Trocki and Lauren Potter from the hit TV show *Glee*. They will be joining us for the Opening Plenary, plus we'll be airing a taped message from *Glee*'s Jane Lynch.

Pioneer K. Charlie Lakin, Ph.D., is the recipient of this year's Research Matters! Award. Dr. Lakin's distinguished work as an innovator and activist has immeasurably advanced the lives of people with I/DD. Dr. Lakin has over four decades of experience as a teacher, researcher, consultant, and advocate focusing on

“It is marvelous that in 2010, persons with disabilities can purchase their own home, get married and direct their own lives.”

— Cindy Johnson,
National Board Member
of The Arc and Real
Estate Consultant

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Mission Statement

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

a home of our own: that is the way we all want to live!

National Board member of The Arc and Real Estate Consultant Cindy Johnson merged her passion as an advocate with her vocation when she worked with a couple with intellectual and developmental disabilities to purchase their own home in Plymouth, Minnesota.

When Cindy met Hunter Sargent and his fiancée Holly Turley, she was enthusiastic about the opportunity to work with them. “Of all the clients I have worked with, I really enjoyed helping Hunter and Holly. It is marvelous that in 2010, persons with disabilities can purchase their own home, get married and direct their own lives. That is the way we all want to live!” Johnson said.

“With the support and encouragement of The Arc, Hunter and Holly caught the home ownership bug. They attended a first time home-buyer class and I helped them get pre-qualified for a loan,” Johnson said.

Cindy has lived for two generations with family members who have significant disabilities. She has a 49-year-old sister who lives in a group home and is severely disabled, both physically and cognitively. She is a co-guardian for her sister. Her commitment to disability rights is fueled by having lived through a time with her sister where the only option for supports was the state hospital; she saw her sister removed from the family home at 13 and placed in an institution.

Her daughter, Jenna, is 26 and has cerebral palsy and learning disabilities. As a disability policy advocate for over two decades, Cindy has fought tirelessly to ensure the services and supports Jenna receives are maintained so she has a better quality of life.

In her role as a Real Estate Consultant with Dona Christensen Realty in Twin Cities, she recently worked with former The

Arc of the United States board member, Cliff Poetz, to find a home of his own. Cliff lived in a large ICFMR/Institution prior to getting his own apartment in public housing.

He always nurtured a dream to own his own home and recently signed a contract for a one bedroom condo in a lovely suburb of Minneapolis in the same condo building

as the newlyweds Hunter and Holly Sargent. Cliff will have his own patio/deck, washer, dryer, and fireplace.

Cliff was able to access first time homebuyer money through the city and a Federal loan that reduces the principal mortgage and provides half of the down payment and

all the closing costs. The Arc of Minnesota, for which Cliff serves as a Board Member, and other friends recently hosted a house warming gathering to get him off to a good start in his condo when he moves at the end of September.

Cindy is a member of The Arc of Minnesota and was elected to The Arc of the United States Board of Directors in 2001; she has served on the Governmental Affairs Committee since 2000. She was appointed to the Disability Policy Collaboration Steering Committee at its inception and is currently Co-Chair of the DPC and GA Committees of The Arc.

The Arc is grateful to Cindy for her years of committed service as an advocate, parent and family member; as her term comes to a close, we extend our deepest gratitude for her dedicated service on the national board for the past eight years. ■



Cindy Johnson with Holly and Hunter Sargent



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quality of life issues. He is the Director of Research and Training Center on Community Living at the University of Minnesota.



K. Charlie Lakin, Ph.D. “Perhaps no one more than Dr. Lakin has demonstrated through research that the evolving national commitment to community services is well-founded and beneficial to persons with disabilities. It is with great pride that The Arc presents him with this year’s Research Matters! Award,” said Peter V. Berns, CEO of The Arc.

Self-Advocates Shine

Self-advocates will shine at Convention where the program will include powerful self-advocate leaders sharing their experience being in charge of their own lives, speaking up on their own behalf and achieving their personal goals. The Arc of Florida will have more than 250 self-advocates in attendance at Convention.

Self-advocate Yayo Robles from Advocacy in Action, LLC will present “Living the Dream” exploring the dramatic circumstances of his life and his successful pursuit of his creative dream.

At the age of 9, Yayo was hit by a car and pronounced dead at the hospital. He was revived but remained in a coma for eight months.

After years of therapy and special education, he is now successfully realizing his dream of a career in film-

making and acting. Yayo will share his experience of overcoming attitudinal barriers to be able to lead a self-determined life and pursue his dreams.

In a presentation titled “Don’t Give Up!,” self-advocate Jamie Lazaroff describes what he calls “One-person’s journey through life that happens to have an intellectual disability. It is a story of where I was, where I am now and where I would like to be. I live by a mantra of ‘don’t give up, don’t ever give up.’”

“I will also talk about how we all need support and a circle of friends. I will talk about my experiences at setting the bar high and having expectations for people with intellectual disabilities,” Lazaroff said.

Co-Executive Director of The Arc of Northern Virginia and self-advocate Jill Egle will conduct a workshop on “A Life Like Yours Toastmaster Program.” This empowering training session will inform other self-advocates about knowing their rights, speaking up on their own behalf and standing up for their rights.

The Arc & Sprout Launch National Film Festival

The Arc is partnering with Sprout, the nation’s leading showcase for films related to intellectual and developmental disabilities, to provide our chapters with a turnkey film festival event launching with 25 participating communities across the country.

In partnership with Sprout, The Arc will provide promotional assistance and guide state and local chapters through creating an amazing cinematic experience for communities.

The Festival will be officially intro-

duced at Convention, where Sprout will hold a film festival event on Wednesday, November 3. Sprout Founder and Executive Director Anthony Di Salvo will share the vision and perspective for each of the films showcased that evening.

The Arc – A New Look & Feel

After many years of waiting and in response to research and our professional and volunteer leadership, The Arc has crafted a whole new brand identity to take us into the next 60 years. Share in the excitement when the new logo and tagline are revealed for the first time. Our new look and feel will help propel our revitalized organization into the future. CoreBrand, a nationally acclaimed branding firm is working with The Arc to redefine our identity and build a stronger national brand for the next 60 years.



Jill Egle, Co-Executive Director, The Arc of Northern Virginia with William Washington, Receptionist, The Arc’s national office

spotlight on donor nancy webster: “the sibling role is key”

Nancy Webster, a member of the National Board of The Arc since 2002, recalls being nine or ten years old when her parents went to New York state with a group of other parents in search of educational support for their children with disabilities.



“There were very few community-based services in Illinois and my parents interviewed a teacher from The Arc in New York who came and lived with us for a while,” she said. “I don’t remember not knowing The Arc.”

Nancy has a lifetime of experience with people with disabilities as a sibling to her sister Martha who is five years younger. “Of course I think the sibling role is key. My experience with siblings of my generation is that our parent’s generation was trying to protect ‘normal children’ from having to take care of their siblings. Many siblings I know don’t take care of their siblings because it wasn’t part of their routine. My parents engaged us in how we were going to make her [Martha] as independent as possible,” Nancy said.

Nancy is an active caregiver and decision maker in her sister’s life as are her husband Bob and their adult chil-

“I think she lives a terrific life and I think she would say she lives a terrific life.”

— Nancy Webster
about her sister Martha

dren. “When our mother died, Martha chose to stay in Fort Wayne, Indiana. She felt strongly about staying there because that’s where her friends and her job are. Moving to Illinois would have meant being on a waiting list for eight years,” Webster added.

Martha became eligible for a Medicaid waiver a couple of years later and moved into her own apartment. Today, she lives in Fort Wayne, IN with two housemates in a three bedroom apartment and receives support from staff.

Both Nancy and Martha are connected to The Arc – Martha recently

agreed to join her sister in making a contribution to The Arc for its rebranding effort saying, “Everybody should know who The Arc is.”

Siblings can assume parenting, caregiver and friendship roles and Nancy believes it is a place of honor. “There’s that pride of being a sibling. I look at Martha and think: look at what she can do! Whether you grow up with a sibling with a disability or not, you don’t know what that person will do when they’re 40 when you’re 14.”

“We don’t give opportunities for siblings to celebrate each other. Over the last 60 years we have championed parents who have created opportunities and we need to champion siblings too. One of the things Martha talks about, since everybody in our family but us has died, is that we’re a really great team. Oftentimes Martha says don’t you think Mom and Dad would think we’re cool for working with The Arc?”

Currently, Nancy chairs the Committee on the Future of The Arc, which was charged with developing a strategic plan – the “Strategic Framework for the Future of The Arc, 2010 – 2019.” Under her leadership, the Committee on the Future of The Arc is working to strengthen the chapter and membership structure in order to accomplish The Arc’s new plan.

Prior to joining The Arc Board, she was active with The Arc of Illinois from 1992 to 2002, serving as Board President from 1998 to 2001. Like Martha, you can join with The Arc to improve the lives of siblings, children and other people you may know with I/DD. Your involvement helps not only those close to you but millions of others across the country. Visit www.thearc.org to find out more about how you can support The Arc. ■

So Many Ways...

With your support, The Arc promotes and protects the human rights of the more than seven million individuals and their families in the U. S. who are living with intellectual and developmental disabilities. Together we can make things happen through individual and family resources, early intervention services, employment, educational and residential support and self-advocacy initiatives.

What's Your Way?

- **Make a contribution with the card below.**
- Attend The Arc's National Convention or other upcoming events.
- Become a member.
- Become an advocate.
- Support The Arc nationally so that we can help our chapters.
- Sign up to receive Action Alerts or The Capitol Insider e-news from our public policy team.
- Find out more about planned giving, gifts of stock, property and the Combined Federal Campaign.



Explore our new,
expanded Web site at
www.thearc.org today and
discover all of the ways you can help.

What's Your Way?

- ☐ Yes! I want to support The Arc.
 ☐ \$50 ☐ \$100 ☐ \$150 ☐ \$_____ Other ☐ \$_____ Monthly
- ☐ Yes! I want to become a monthly sustainer.
- ☐ Yes! Count on me to work to improve the lives of those with I/DD.
- ☐ Yes! I want to receive e-updates with the latest news from The Arc.
 My e-mail address is: _____
- ☐ I support The Arc because I have a child, grandchild, sibling, friend,
 co-worker or _____ with I/DD.

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ D.O.B. _____

- ☐ Check or money order enclosed
- ☐ Please charge my ☐ VISA ☐ MasterCard ☐ AMEX ☐ ArcVISA
- Card # _____ Exp. Date _____
- Signature _____
- ☐ My company will match my gift

Use this card and the attached envelope for your gift. *Thank you for your generosity.*



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The Arc of the United States is a non-profit organization located at 1660 L Street, NW, Suite 301, Washington DC 20036. The information enclosed describes one or more of The Arc's activities. Your gift is very much appreciated and is tax-deductible as a charitable organization to the fullest extent allowed by law. A copy of The Arc's current audited financial statement may be obtained by writing to The Arc at the above address, by calling 1-800-433-5255, or via email at donorsupport@thearc.org. If you are a resident of the following states, you may obtain information directly by contacting: *Florida—a copy of the official registration and financial information may be obtained from the Division of Consumer Services by calling toll free within the state 1-800-HELP-FLA. Florida registration #CH1140. Maryland—for the cost of copies and postage, documents and information submitted by the organization are available from the Secretary of State. *Mississippi—the official registration and financial information of the organization may be obtained from the Mississippi Secretary of State's office by calling (888) 236-6167. *New Jersey—information filed with the Attorney General concerning this charitable solicitation and the percentage of contributions received by the charity during the last reporting period that was dedicated to the charitable purpose may be obtained from the Attorney General of the state of New Jersey by calling (201) 504-6215 and is available on the Internet at www.state.nj.us/lps/ca/. New York—a copy of the latest annual report may be obtained from the organization or from the Charities Bureau, Department of Law, 120 Broadway, New York, NY 10271. *North Carolina—financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at (898) 830-4989. *Pennsylvania—the official registration and financial information of The Arc of the United States may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, (800) 732-0999. Virginia—a financial statement is available from the State Division of Consumer Affairs. Washington—additional financial disclosure information may be obtained with the Secretary of State at (800) 332-4483. *West Virginia—residents may obtain a summary of the registration and financial documents may be obtained from the Secretary of State, State Capitol, Charleston, West Virginia 25305.

*Registration with any state agency does not imply endorsement, approval or recommendation by the state.

10JLMC

eta phi beta continues to support the arc

by Trudy Jacobson, Chief Development & Marketing Officer, The Arc

Early on the morning of July 26th, I boarded a plane from Baltimore to Chicago to help kick off the second Gloria Chapmon Walk-A-Thon for the Intellectually Disabled. I was honored to attend and represent The Arc, yet at the time, I knew little about the sponsor, the Eta Phi Beta Sorority.



Trudy Jacobson with members of Eta Phi Beta Sorority

I learned that Eta Phi Beta Sorority is one of the nation's premier business and professional women's organizations. The sorority was the dream of eleven distinguished African-American professional women of vision in Detroit, Michigan in 1942. They joined in common purpose to realize a powerful sisterhood that would provide a space to connect, express and share. Their historic vision was

to promote high scholastic standards, personal growth and career awareness and provide opportunities for community service.

As part of their purpose statement, Eta Phi Beta pledges to "assist in programs designed to improve the quality of life for people who are developmentally disabled." They have worked tirelessly to achieve these objectives in part through

continuing support for The Arc on behalf of those with intellectual and developmental disabilities. Their motto "Not For Ourselves, but for Others," is a testament to their commitment to The Arc and to people with disabilities.

In 2008 Lynne Cleveland, our national Board President, attended the first Gloria Chapmon Walk-A-Thon for the Intellectually Disabled in Houston and I was proud to join their bi-annual Boulè. When I walked into the brimming hotel ballroom at the McCormick Place Hotel, I was met by a vibrant assemblage of women dressed in their sorority colors of red and gold. Following a heartwarming tribute to the organization's founders, we all gathered in front of the hotel for pictures and I

had the honor of meeting Ms. Chapmon, as well as Rev. Jean Dade-Batchie, The Grand Basileus of Eta Phi Beta.

The Co-chairs of this year's event were Dr. Jewell Cristy of Houston and Alma Handy-Simmons, former national board member of The Arc and the organization's Executive Director. Dr. Cristy is the mother of two sons with disabilities and was so inspired by the work she learned to do on behalf of her sons that she became an educator.

In addition to their generosity to The Arc nationally, Eta Phi Beta also provided a contribution to The Arc of Illinois. Anthony Paulauski attended the Merits and Awards Breakfast on the last day of this year's Boulè to thank them for their generosity to the state chapter.

We extend a heartfelt thank you to the women of Eta Phi Beta for their continuing support and generosity, and hope that this relationship will grow in the future. If you are interested in learning more about the good work of Eta Phi Beta, please visit their website: www.etaphibetanational.com ■

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Hammer Travel has joined us as a Convention sponsor this year; this dynamic company offers a variety of travel opportunities for individuals with developmental disabilities. They are coordinating trips to Convention, including customized travel arrangements for people with I/DD and their families. Their convenient packages include: lodging, staffing, food, Convention registration, and area attractions/activities. Please visit www.hammertravel.org or call 1.877.345.8599 to get more information or make travel arrangements.

Hammer Travel offers destinations which are exciting and unique, while providing well-trained staff to accompany each group, ensuring a safe, fun and memorable travel experience for our constituency who deserve the same rich experiences we all get from travel and touring. Hammer Travel shares The Arc's mission to respect individual preference for the population we both serve, while working to meet the unique needs and desires of all travelers. ■

A Clear Way Forward

The Arc's National Convention

Hilton in the Walt Disney World® Resort
Lake Buena Vista, Florida
November 3 – 6, 2010

**Early Registration
Ends October 1!**

Reserve your spot now
and save, or visit
www.thearc.org for
more information and
register online.



The Arc is charting "A Clear Way Forward" and calling community members, families, self-advocates, professionals, and volunteers to join us this November for our National Convention. Network, learn and recharge...and enjoy yourself in sunny Florida!

The "Don't Miss" List

Here are just some of the more than 30 inspiring and informative sessions we have planned for you!

- Succession Planning for Executive and Board Leadership: Proven Practices to Sustain Effective Organizations – A pre-conference session (check registration information)
- What's Happening with the New Health Care Law? – Information and advice about the implementation of the Affordable Health Care Act
- Stand Up!: The SEEDS Project – An anti-bullying initiative for students, parents and educators
- Pack My Bags. I Am Heading to College! – A panel discussion on the challenges and rewards for students with I/DD attending college
- A New Generation of Civil Rights Music: Community Organizing through Song & Dance

And be sure to join us as we celebrate The Arc's 60th anniversary and introduce our new brand identity, which will propel our revitalized organization into the future!

Calling All Gleeeks!



Actresses Lauren Potter and Robin Trocki from the hit TV show *Glee* will be joining us for the Opening Plenary Session. Won't you?

What You Need To Know

The Arc's 2010 National Convention will be held at the Hilton in the Walt Disney World® Resort, across from Downtown Disney® in Lake Buena Vista, FL.

Room rate is \$135/night

++ Special rate is only available until October 4th. Space is limited, book now.

The Orlando International Airport (MCO) is 15 miles from the Hilton in the Walt Disney World® Resort and the average driving time is less than 25 minutes.

Visit www.thearc.org for a list of airline carriers, discount shuttle services, driving directions, and other important travel information. Hotel parking is complimentary for convention attendees.

New in 2010 – Hammer Travel will be coordinating trips to The Arc's 2010 National Convention including customized travel arrangements for individuals with intellectual and developmental disabilities and their families. Their convenient packages include: lodging, staffing, food, Convention registration, and area attractions/activities. Call 1.877.345.8599 or visit www.hammertravel.org

place
postage
here



The Arc
Attn: Convention Registration
1660 L Street, NW, Suite 301
Washington, DC 20036

Register before
October 1, 2010 and SAVE!

REGISTRATION FORM: The Arc's National Convention

Full Convention Registration	Before 10/1/10	Late & Onsite
<input type="checkbox"/> Member of The Arc	\$375	\$450
<input type="checkbox"/> Non-member	\$475	\$550
1. SUBTOTAL \$ _____		
Full Convention fee includes: Official Convention bag, commemorative pin, access to all official Convention sessions, Thursday Opening Exhibit Hall Reception, Friday Apron Luncheon, and breaks.		

One-Day Convention Registration	Before 10/1/10	Late & Onsite
Member of The Arc <input type="checkbox"/> Thurs <input type="checkbox"/> Fri	\$200	\$250
Non-member <input type="checkbox"/> Thurs <input type="checkbox"/> Fri	\$250	\$300
Self-Advocate or Personal Care Assistant <input type="checkbox"/> Thurs <input type="checkbox"/> Fri	\$99	\$99
2. SUBTOTAL \$ _____		
One-Day fees include: Official Convention bag, commemorative pin, access to one-day of sessions and advertised meals.		

Pre-Conference (Sponsored by NCE and The Arc)	Before 10/1/10	Late & Onsite
<input type="checkbox"/> Pre-Conference Package*	\$250	\$300
<input type="checkbox"/> Pre-Conference Only*	\$175	\$225
3. SUBTOTAL \$ _____		
*Pre-Conference Package fee includes: Pre-Conference, Wed. Lunch and NCE Annual Reception & Awards Dinner. This fee does not include the Convention Registration Fee. Note: Pre-Conference Only does not include a ticket to the NCE Awards Event.		

Ticketed Events	
NCE Awards Dinner	___ x \$ 75 = \$ _____
Sprout Film Festival	___ x \$ 15 = \$ _____
The Arc of Florida Award's Luncheon	___ x \$ 35 = \$ _____
The Arc's Research Luncheon	___ x \$ 45 = \$ _____
The Arc's Opening Celebration	___ x \$ 40 = \$ _____
The Arc's Closing Banquet	___ x \$100 = \$ _____
Transfer to <i>Magic Kingdom</i> ® Park (Saturday Only)	___ x \$ 10 = \$ _____
4. SUBTOTAL \$ _____	

Attendee type:

- ☐ I am a member of The Arc.
☐ I am NOT a member of The Arc.
☐ I am a Self-Advocate or Personal Care Attendant

Is this your first time attending Convention?

- ☐ Yes ☐ No

How did you hear about The Arc's Convention?

- ☐ Magazine ☐ E-Mail from The Arc
☐ Local Chapter ☐ Empower Newsletter
☐ State Chapter ☐ Direct-mail Brochure
☐ Fusion E-Newsletter ☐ Other _____

Chapter Involvement:

- ☐ Local President ☐ Chapter Volunteer
☐ Local Executive Director ☐ State President
☐ Membership Coordinator ☐ 2010 Delegate
☐ Other _____

Convention T-shirt Size:

- ☐ S ☐ M ☐ L ☐ XL ☐ XXL
☐ I would like to opt out of receiving a T-shirt.

Total Fees from All Boxes

1. Full Convention Registration	\$ _____
2. One-Day Convention Registration	\$ _____
3. Pre-Conference	\$ _____
4. Ticketed Events	\$ _____
Voluntary Contribution (to support Self-Advocates participation)	\$ _____
GRAND TOTAL ENCLOSED \$	\$ _____

☐ Check here if you require special assistance to fully participate and attach a written description of your needs.

Payment Information

- ☐ Check (Payable to The Arc)
☐ Visa ☐ Mastercard ☐ Amex

Name: _____
Exp. Date: _____
Credit Card #: _____
Signature: _____

Print Name (First, M.I., Last) _____
Title _____
Chapter / Organization _____
Address _____
City _____
State _____ Zip Code _____
Phone _____
Fax _____
E-mail _____

REFUND POLICY: All refund requests must be received on or before October 15th. NO EXCEPTIONS. Please send your request to Robin Powers at robin@cmig.com. There will be a \$25 processing fee for all refund requests. No refunds are given for no-shows. Refunds will be processed after the Convention.

QUESTIONS: Please e-mail us at events@thearc.org.

Please check all that apply:

- ☐ Self-Advocate
☐ Personal Assistant
☐ Family Member - Parent
☐ Family Member - Sibling
☐ Family Member - Extended
☐ Student
☐ Educator/Teacher
☐ Professor/Researcher
☐ Government Personnel or Official
☐ Attorney
☐ Volunteer
☐ Chapter Staff
☐ Direct Support Professional
☐ Professional in the Disability Field
☐ Other _____

Mail or Fax (919-782-5131) to:

The Arc
Attn: Convention Registration
1660 L Street, NW, Suite 301
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Register online: www.thearc.org

celebrating our victories in medicaid and education

The Arc is celebrating the additional \$16.1 billion in Medicaid funding and \$10 billion in education funding that states can receive for 2011. The Teacher Jobs and State Fiscal Relief bill signed into law by President Obama on August 10 includes the federal funding for state Medicaid programs and school systems.

Enactment of the law brings significant relief to advocates from across the country that had been bracing for further budget cuts to home- and community-based services (HCBS) as well as special education teacher layoffs. However, according to The Arc's Paul Marchand, "since the majority of states continue to face severe shortfalls in revenue, we can still expect to see some cuts, though they will be much smaller than we had feared."

"Protecting core services has been the number one priority this year and we are thrilled that this law finally passed," says Jamie Liban, the Executive Director of The Arc of Virginia. "With the additional Medicaid funding, our state will be issuing 250 new Intellectual Disability waivers for families on the waiting list and will avoid a 5% cut in reimbursement rates, a 66% cut in respite hours and reductions in assistive technology and environmental modifications in

the first year of the budget. This would not be possible if it were not for the tremendous advocacy efforts of people with developmental disabilities and their families. While we are grateful for the (temporary) moment of relief, we are reminded that we must remain vigilant in order to ensure people with developmental disabilities and their families have access to critically needed supports and services."

Attention now turns to governors who just learned that they must apply for these funds. The Arc will be working to activate our state and local grassroots network to make sure governors take advantage of this opportunity to protect Medicaid and education services for people with intellectual and developmental disabilities. ■

FINDS survey update

The Arc has heard from more than 4,500 individuals with intellectual and developmental disabilities (I/DD) and their families on The FINDS (Family and Individual Needs for Disability Supports) Survey. Are you a family member, self-advocate or professional caregiver? There is still time for you to participate and take the survey. Read on to find out how.

This unprecedented national study will help The Arc engage individuals with I/DD and their families in a meaningful way to understand what they need, what services and supports they have, and what they want for their futures.

The Arc is collaborating with more than a dozen national organizations, and in an effort to increase our outreach, we recently partnered with the National Military Family Association (NFMA) and other military channels to distribute a special version of the survey (<http://www.surveymonkey.com/s/TheArcFinds2010forMilitaryFamilies>) to as many military families who have a family member with a disability as possible.

We need to gather as many completed surveys in individual local and state communities as possible so we may provide results on these services and supports that impact you in your local community. In the fall, The Arc will also launch a chapter census to better inform us of what is offered by each of our chapters across the nation. It will also tell us how what we are offering meets the needs of those we serve.

We are grateful to Chapters of The Arc and all of our partner organizations who are continuing to help us to promote The Arc FINDS.

- American Association on Intellectual and Developmental Disabilities
- ANCOR

- Association of University Centers on Disabilities (AUCD)
- Autistic Self Advocate Network
- Best Buddies
- Exceptional Family Member Program (Department of Defense)
- National Association of Councils on Developmental Disabilities
- National Council on Independent Living
- National Association of State Directors of Developmental Disabilities Services
- National Military Family Association
- Office on Disability Employment Policy in the Department of Labor
- Self Advocates Becoming Empowered
- The Sibling Support Project

We urge individuals with I/DD, family members, caregivers and others to participate in The Arc FINDS survey at <http://www.surveymonkey.com/s/TheArcFinds2010>. Questions? Contact Ann Cameron Caldwell at 202.534.3711 or Caldwell@thearc.org. ■

nation. In health services for elderly patients and people with disabilities, hospitalization wait times for those experiencing mental health issues are increasing.

Some elderly patients arriving at Alaska Psychiatric Institute are experiencing age-related health issues, rather than mental health issues.

The same is true for people served by The Arc; sometimes they experience episodes of extreme behavior that is not really a mental illness. Patients are ending up at API because there are few other resources available to them in Anchorage.

“The Anchorage hospital also is seeing more developmentally disabled patients, whose cases are particularly complex,” said Ron Adler, API chief executive.

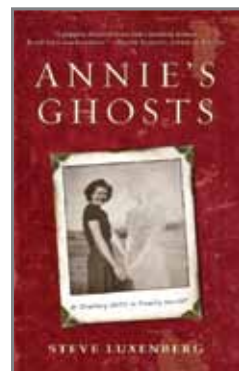
“Every person and situation is different, but sometimes people are hospitalized when all they really need is to be removed from a stressor while they de-escalate,” said Laronsia Reynolds, Director of Behavioral Services for The Arc of Anchorage.

There are a limited number of beds available to mental health patients in Anchorage. API can safely serve 80 people. When API is at capacity, patients turn to local hospitals where they can wait days and sometimes weeks for a bed to open at API.

The Arc of Anchorage’s crisis housing center will decrease the demand for unnecessary placement at API and save beds for those situations where hospitalization is the best solution. ■

good reads

Journalist Steve Luxenberg’s new book takes a personal journey back to a time when people with disabilities lived in the shadows – hidden from society and sometimes from their own families.



“*Annie’s Ghosts*” is a frank reminder of a time before organizations such as The Arc worked to empower people with intellectual and developmental disabilities. Here, in his own words, he gives us a glimpse at the jarring juxtaposition between the tragedy of his aunt’s life in the first part of this century and the opportunities that would have been available for her today. His book allows us to see not only where we’ve been, but where we are and just how far our movement has come.

By Steve Luxenberg

The best documentaries, said one creator of that art form after a recent screening in Baltimore, reveal something that is outside the experience of those watching the film.

His words resonated for me. For the past several years, I have immersed myself in the life of someone I never knew, someone whose daily routine couldn’t have been more different than mine. She was my aunt, and she was a family secret.

More precisely, she was my mother’s secret. Mom never talked about having a sister, and only after Mom’s death did the first wisps of her secret come into the light.

Her name was Annie Cohen. She had physical and mental disabilities that came to define her and her existence. I know now, based on medical records unearthed from a mental hospital, that Annie wanted nothing more than to be like other girls, to live a “normal” life, hold a job and live independently. But she was born at a time (1919) and place (Detroit) that dictated a different fate.

In the spring of 1940, Annie’s increasingly erratic and paranoid

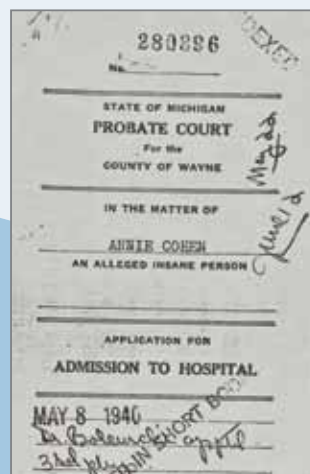
behavior drove my grandmother into the arms of a local hospital. There, a neurologist told her that Annie probably belonged in an institution for the feeble-minded, in the language of that time, but that there was a waiting list. He recommended commitment to a public mental hospital as a temporary measure.

My grandmother followed his advice, signing a court petition that set off a rapid chain of events. Within two weeks, on the eve of Annie’s 21st birthday, she was escorted to Eloise, the Wayne County mental institution. She stayed for 31 years, until not long before her death.

In the parlance of that era, Annie and her fellow patients took on the same status as those serving prison sentences. They were “alleged” to be insane, they were “inmates” in the institution, they were “paroled” upon discharge. The main

difference between a mentally ill patient and a criminal at that time? A criminal had more rights.

We have in our heads an image of the bygone public mental hospital, with warehoused patients living in awful conditions. There’s truth in that image, of course, but it doesn’t begin to explain the complex, evolving reality of mental health treatment in the United States over the



past 150 years. The overseers of Eloise Hospital saw themselves as progressive reformers, dedicated to making their patients' lives better. That's what I found so fascinating. We now regard lobotomies with appropriate horror, and yet the man who gave us the lobotomy won a Nobel Prize for his work in 1949.

In Annie's day, treatment often meant institutionalization, which meant an inexorable growth in the mental hospital system. Today's laws regarding involuntary commitment contain multiple safeguards to protect patients against being sent to institutions against their will. The legal burden has shifted to the police, the courts and the doctors. They must prove that patients are a danger to themselves or others, which has been the standard for involuntary commitment since the late 1960s.

Sending Annie to Eloise labeled her as mentally ill. The doctors and staff there would have known of the tests showing an IQ level somewhere between mild and moderate retardation. But they wouldn't have focused on it. Ed Missavage, a psychiatrist who worked at Eloise for nearly 30 years, reviewed her records for me and pronounced her as the prototype of "a custodial patient."

What did he mean? I asked.

"She's the type we don't ever think is going home," he said.

My grandparents didn't know how to care for her, and the hospital would be reluctant to release her if she had nowhere to go and no way to support herself.

Women without disabilities had trouble finding their place in the workforce in those days. How could a woman with disabilities find one? Today's group homes didn't exist

then. Neither did programs aimed at providing training and jobs for the developmentally disabled, the phrase that governments now use in place of retarded and feeble-minded.

Experts who examined Annie's records said they thought if she were living now, she might have a shot at finding and holding a job. She could read, and she had enough self-awareness to tell a social worker that she wanted to be like other "normal" girls.

She never got that chance. At some point, she went from custodial patient to warehoused patient, existing more than living. How she spent her days is still pretty much a mystery to me. How she spent her life is a reminder of where we have been, and how much farther we can go. ■

Steve Luxenberg is an associate editor of *The Washington Post*, and author of *Annie's Ghosts: A Journey Into a Family Secret*, published in May 2009 by Hyperion.

***Managing a Special Needs Trust: A Guide for Trustees* (DisABILITIES-BOOKS, 2010) is a valuable reference guide for anyone managing a special needs trust for a person with a disability and/or working with their families on future planning. The book explains how special needs trusts relate to the many complicated public benefit programs that assist people with disabilities.**

In clear, understandable language, the book explains how a trustee can use the trust funds for the medical, recreational, and transportation needs of a beneficiary with a disability without risking government program benefits such as SSI, SSDI, Medicaid, and Section 8 housing. It provides many practical examples for readers to follow.



Managing a Special Needs Trust: A Guide for Trustees by Barbara D. Jackins, Esq., Richard S. Blank, Esq., Ken W. Shulman, Esq., and Harriet H. Onello, Esq., is for parents, individuals with disabilities, family members and advocates as well as attorneys, financial planners, tax advisers, social workers and educators—anyone who is managing a special needs trust and/or working with families on future

planning for a family member with a disability.

This publication is a completely revised, updated, and expanded edition of *Special Needs Trust Administration Manual: A Guide for Trustees* (2004, 2005). Although earlier editions focused almost exclusively on Massachusetts laws and procedures, over 10,000 copies were sold across the USA. The new 2010 edition applies to all 50 states.

Trustees will find practical strategies to:

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The book costs \$24.00 plus \$4.50 for shipping.

The Arc receives a portion of sales to members and friends. When purchasing online, in the "Redeem Coupon" box, please enter: Arc. If purchasing by mail (DisABILITIESBOOKS, 33 Pond Avenue, #919, Brookline, MA 02445) or telephone (617-879-0397), please mention that The Arc is to be credited. ■



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