



empower

Real People, Real Progress

Issue 6 | Summer 2011

the road ahead: an interview with Marty Ford



Marty Ford,
Director, The Arc's
Public Policy Office

Marty Ford recently became director of The Arc's Public Policy Office, taking over after the retirement of her mentor for the past 26 years, Paul Marchand. Marty is a proven leader in the disability community and a nationally recognized expert in Social Security,

Medicaid, and long term services and supports. We sat down with Marty to learn about the direction she sees for The Arc's public policy efforts.

Q. What is The Arc's top policy priority?

A. Medicaid will be our number one priority for at least the next year while the federal deficit takes center stage on Capitol Hill. Medicaid pays for the vast majority - 78% - of long term services and supports for people with I/DD. These include all home and community-based waiver services.

Q. What is happening with Medicaid?

A. Some Members of Congress want to block grant Medicaid. They also want to cut funding for it - by 20% over 10

years - and to cap the amount that the federal government pays for its share.

Q. What is the problem with block granting Medicaid?

A. States would get less federal money for health care for people with disabilities. States would have much more flexibility to cut out certain groups of people or certain services. People with I/DD stand to lose services they need to stay in their homes and communities and out of institutions and other services such as prescription drugs, physician services, and physical therapy. The list is very long and these are but a few examples. There will be no more guarantee of services and waiting lists could grow even longer.

Q. What would you ask advocates to do about this?

A. We need to be out on the front lines at town hall meetings, meeting with our Members of Congress in their district offices, and writing letters to the editor of our local papers about not cutting Medicaid in favor of paying for tax cuts for the wealthy. We need to put a face on this issue and it needs to be ours. We need to tell how our lives will be

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Disability Policy Collaboration now The Arc's public policy office

The Disability Policy Collaboration (DPC), formerly a joint venture of The Arc and United Cerebral Palsy, is now at home under the banner of The Arc. The Arc and UCP amicably dissolved their partnership effective April 1. Marty Ford, named acting director after the retirement of long-time leader Paul Marchand in January, is now Director of the Public Policy Office and will lead a team which includes Annie Acosta, Maureen Fitzgerald, Julie Ward and TJ Sutcliffe. The team will continue to do the same amazing job of monitoring and protecting the interests of the intellectual and developmental disability community, only now under the name of The Arc's Public Policy Office. ■

The Arc's Legislative
Agenda for the
112th Congress is
now available online
at www.thearc.org.



"the governor heard our voices"

Florida Backs Down from Cuts in Wake of Protests

In April, Chapters of The Arc in Florida were dismayed to learn of an eleventh hour across the board 15 percent funding cut for state services ordered by the governor. The 15 percent would come on top of already deep cuts that have directly impacted organizations that provide services for people with intellectual and developmental disabilities (I/DD), forcing some to shut down, force staff layoffs, or potentially leave clients in undesirable situations.

Kathy Jackson, the executive director of The Arc of the St. Johns, immediately took to the airwaves to oppose the cuts and offer constructive help to the governor, who is facing pressure to reduce spending. Kathy outlined ideas on how services can be provided more efficiently to maximize fiscal responsibility on local radio, offering the expertise of the 42 affiliated Chapters of The Arc in Florida. And, she encouraged an active voter-registration drive to give the tens of thousands of individuals with I/DD a voice at the polls.

Also, hundreds of protestors, many associated with The Arc, trekked to Tallahassee to speak with Governor Scott directly. The protestors eventually met with his budget staff and shortly thereafter the governor rescinded the order, as the Florida legislature agreed to fill a deficit in the Medicaid program to avoid the cuts.



Supporters of The Arc of the St. Johns at the Governor's office in Tallahassee, FL

Deb Linton of The Arc of Florida said the next step is for the disability community to meet with the governor to discuss the deficit and take positive steps toward solving budget issues. Echoing The Arc of the St. Johns public offer to help the state find budget solutions without cutting services, Deb said: "We need to be open, transparent and look at everything. The governor's office can't solve this by themselves." While these specific cuts have been rescinded, budget issues still threaten the foundations of support for people with I/DD if not resolved before the next fiscal year begins in July.

"The governor heard our voices," Linton said, "I'm glad he listened." ■

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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.

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upended. Parents need to talk about having to quit a job to care for their child or deplete retirement and college savings accounts. Self advocates need to tell how they may lose their supports for living independently in the community and their fears of institutions.

Q. What should advocates be telling their Members of Congress?

A. They should tell their two Senators and their Representative: Do not block grant or cap Medicaid. Do not slash funding for services that help people live and work in the community. Do not put the health and safety of people with I/DD at risk by block granting and cutting funding for Medicaid. It is important to get this message out to every Member of Congress, no matter their political party.

Q. How can advocates stay informed?

A. That is the easy part. They can sign up for action alerts and weekly legislative updates at:
<http://capwiz.com/thearc/mlm/signup/> ■

ARCCorps volunteers make a difference

With no family or friends, Michael's situation was dire. As an individual with developmental disabilities, he was non-verbal and spent most of his time alone. Michael desperately needed someone to ensure his rights were protected, to encourage his participation in decisions to the maximum of his ability, and to help him develop life and social skills. In other words, Michael needed a friend.

Fortunately, he found two - Shouna and Gary Olson. As volunteer guardians for TARC, an affiliated chapter of The Arc in Tulsa, OK, Shouna and Gary provide valuable service through this chapter's

ARCCorps program.

Shouna's and Gary's friendship with Michael made an immediate impact on his life. He had serious health issues. Most apparent was the fact that Michael was dangerously underweight. With the Olsons' involvement, he gained weight.

The Olsons had a positive impact not only on Michael's physical health, but on his social well being. He had been afraid to go into buildings, severely restricting his activities. With Shouna's and Gary's encouragement, Michael agreed to join them one day at an ice cream shop. They arranged for

psychological services to assist Michael with his fears, helping him lead a more fulfilling life. Michael is usually afraid of people, but is now willing to let Shouna hug him and read to him. With the fresh perspectives and caring attention of Shouna and Gary, Michael can now see more of life's possibilities.

This story is not unique. Through the years, ARCCorps volunteers have made a significant difference in the lives of hundreds of individuals, providing companionship, advice, and protection. No special skills are required to be a volunteer advocate -

just a big heart and a few hours a month.

ARCCorps volunteers receive special satisfaction from watching the one they support grow emotionally. More self-confident, more capable of making decisions for themselves, these individuals blossom once they know they have a trusted friend.

For more information on becoming a volunteer guardian, contact TARC at 1-800-688-TARC (8272) or 918-582-TARC or tarc@ddadvocacy.net or contact your local chapter of The Arc about similar programs. ■

better off in prison?

Laura Repke, a staff member of The Arc of San Francisco, and the parent of a son with a developmental disability, recently wrote a moving letter on the online forum of the San Francisco Chronicle wondering if her son might be better off in prison than attempting to survive with the limited support he can receive as an individual with a disability. California, like many other states, is attempting to balance its budget by gutting the services on which her son Rob depends. In her letter, she muses that prisoners are guaranteed three meals a day, health care, and in the case of death row prisoners at San Quentin, a room with a view of the water, while her son no longer has coverage for physical therapy, dental or vision care. Here's an excerpt from her post:

"It is shameful that the most vulnerable citizens are receiving the largest share of the pain. Rob was born 31 years ago, legally blind, with cerebral palsy and intellectual disabilities. Today he is healthy, employed, living with a roommate and paying his taxes. The essential programs that made this possible are supposedly guaranteed by legislation signed by then-Gov. Ronald Reagan in 1969, the Lanterman Act. The law directs the state to provide people with disabilities like autism and Down syndrome with access to housing, health care and employment.

For people with developmental disabilities, the Lanterman Act was equivalent to the Bill of Rights, except more important. Without its practical support, many could not survive outside of grim old-fashioned state institutions (which were vastly more expensive - and now mostly have closed).

It's a particularly bitter irony that I could even consider prison - a far worse institution - as a potential safe haven. But the math is simple. A \$568.6 million cut is approximately 20 percent of state funding for services for people with developmental disabilities. This comes after years of smaller cuts - plus cuts to other services they depend on, like Medi-Cal. The safety net was dismantled years ago. Now we are taking down the tightrope itself. Meanwhile, prisons - protected by a court order - face only a 1 percent cut."

Laura urges Californians to speak up and make themselves visible to their elected officials. With budget woes striking many states along with the federal government, it is more important than ever to take action and make sure lawmakers are responsive. The Arc and other advocacy groups can be an excellent place to start in organizing a groundswell of grassroots support for people with I/DD to have a positive impact on public policy. Find out more about how you can get involved at www.thearcsof.org or www.thearc.org. ■



major waiting list victory in Maryland

Congratulations to The Arc of Maryland and all of the grassroots advocates for people with intellectual and developmental disabilities working with Chapters of The Arc to end state waiting lists for services. Thanks to their efforts, the Maryland General Assembly recently passed an alcohol tax bill championed by the Lorraine Sheehan Alcohol Tax Coalition, a group named after a longtime advocate for individuals with disabilities and their families and a former National Board Member of The Arc. Ms. Sheehan, who passed away last

year, was a parent to a son with a disability and championed The Arc's movement for many years, including working on the passage of this legislation which will serve as a lasting legacy for her. The tax provides \$15 million for the Developmental Disabilities Waiting List. When combined with federal matching funds, it is estimated to provide a total of \$28 million for people who have been waiting for supports, sometimes for years. ■

still in the shadows?

Fifty years ago, President John F. Kennedy called the nation's attention to deplorable living conditions and limited opportunities for then more than 5.4 million people with intellectual and developmental disabilities (I/DD), many in institutions. He formed a panel to prescribe a plan of action. He called on every American to help bring them "out of the shadows" and established a foundation of civil rights protections and support for those with I/DD. The Arc emerged as a strong voice advocating for community living and the appropriate services and supports people with disabilities need to be successful members of their community.

People with I/DD have made extraordinary progress from the days of social isolation and segregated institutions. In fact, 98% of people with I/DD now live in the community. However, our nation still falls short of President Kennedy's vision. The Arc recently conducted a survey of more than 5,000 individuals with I/DD, their families and caregivers to assess the true needs for disability supports. In a major report called "Still in the

Shadows with Their Future Uncertain," we outline the challenges facing individuals and families living with I/DD and make recommendations for remedy including encouraging the public to take action to bring people with I/DD out of the shadows forever. Also, we call on Congress to protect or enact several key provisions vital to the future of people with I/DD. A pattern of reduced funding in education, employment, personal supports, and residential services, will be devastating for the millions that have no other means of obtaining the support they need.

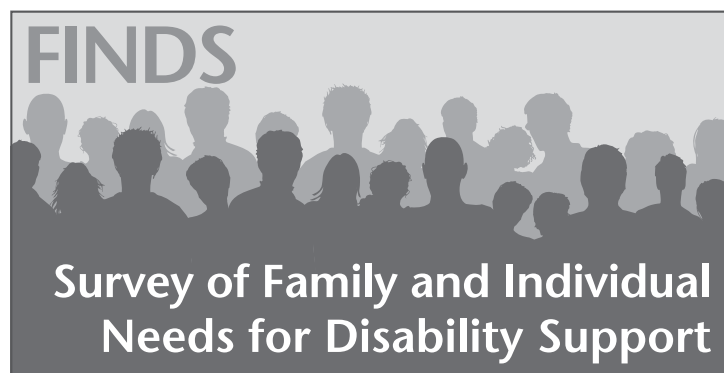
Take a look at some of the statistics from the survey and consider if that status quo is acceptable to you. We are fairly certain you will want to join us to change these realities. Visit www.thearc.org after June 14 to read the full report and take action such as speaking up during political campaigns, registering to vote and voting your conscience in 2012, sharing your thoughts and stories with others and with us, talking to employers about hiring people with I/DD, joining our National Self-Advocates Council or Siblings Leader-

ship Council and more.

Read the full call-to-action to

learn how to get involved at

www.thearc.org. ■



Family and Individual Needs for Disability Supports (FINDS) Survey Data

- Fewer than one-third of students with I/DD are being fully included in primary/middle (29%) or high school (32%).
- 85% of families reported that their adult family members with I/DD was not employed, either part-time or full-time.
- Nearly half (46%) of parents/caregivers report that they have more caregiving responsibilities than they can handle.
- More than 75% of families report they can't find after-school care, non-institutional community care, trained reliable home care providers, summer care, residential care, respite and other services.
- 62% of families report that services are being cut in the community, limiting or eliminating access to community life and opportunities for their family member with I/DD.
- One-third (32%) of parents/caregivers report that they are on waiting lists for government funded services, with the average wait more than five years.
- 80% of families report that they don't have enough money to pay for the support or care their loved one needs and 82% of families report that their overall economic security is challenged. ■

feeling at home

An insider's perspective on working with the new Autism NOW national resource center

By Paula Durbin-Westby, Co-Director of The Arc's Autism NOW

On my desk at the Autism NOW Center sits a photograph of me and my son. The photo was made during the shooting of *Neurotypical*, a documentary about autism. In the photo my son is sitting on my lap as we watch a YouTube video about tornadoes. I admit that I don't often look at the picture when I am in the office: life at the Autism NOW Center is fast-paced, with many important tasks to be done each day. But being a parent is one of the underlying reasons I am working in the field of advocacy and self-advocacy.

I want my child to learn about disability as a natural part of the human experience. I want him to learn to be accepting of human differences. He already is a young advocate for people with disabilities by his open and accepting nature. I once overheard him talking to his Lego Power Miners construction workers. It seems there was a guy with a disability who was the main operator of several of the vehicles. For my son, disability, and including people with disabilities in the "Lego community," is natural.

Being a parent who is on the autism spectrum definitely fits in with Autism NOW and with The Arc. I came to the Autism NOW Center via one of our partner organizations, the Autistic Self Advocacy Network (ASAN). I was impressed that I felt as comfortable working for the Center as I have over the years working for ASAN. Last summer, I presented at The Arc of Virginia's State Convention and immediately felt that same sense of being "at home." My son joined me for part of the conference and often asks me when we can go back.

When I first read about the Autism NOW Center's partner organizations,



Paula Durbin-Westby

I breathed a sigh of relief (you can find a full list of partners at www.autismnow.org). These organizations are committed to ensuring that people on the autism spectrum and with other developmental and intellectual disabilities receive the highest quality services and supports, including employment, community inclusion, support for self-advocacy, and, above all, respect for people with developmental disabilities.

They provide up-to-date technical assistance and ongoing educational opportunities for professionals in the autism field. In short, the Center is a unique combination of self-advocates and cutting-edge organizations engaging in meaningful real-life services and supports, combined with an extensive grassroots network, including chapters of The Arc.

I believe that the work we do at the Autism NOW Center will make the world a better place for people. Not only people with developmental disabilities, but everyone. As we model and carry out in the real world the principles of integration, acceptance of others, self-determination, and community-based inclusion, we will be performing an invaluable service for all people. That's something that fits with my values and makes me proud to tell my son "what we've been doing lately" at the Autism NOW Center. ■



Autism NOW is a national resource and information center functioning as a highly visible, dynamic and interactive central point of quality resources and information for individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, their families, professionals and experts in the field. It was created through a grant from the Administration of Developmental Disabilities as a national initiative of The Arc. You can find out more and access resources at www.autismnow.org. Check out the Center's series of Regional Summits in cities across the country in 2012 and plan to attend one of their weekly free informational and inspirational webinars. And get help finding resources in your community from Autism Now's Information and Referral Call Center toll free at 1-855-828-8476. ■

a daughter's tribute

It's not often that we get a chance to touch the past and feel first-hand how it impacts the lives we live today. Joanne Foster shared a poignant story with The Arc about her mother, Ann Hegarty, which we would like to share with you. More than 60 years ago in Massachusetts, Ann Hegarty and her husband Michael were busy raising Joanne and her brother Mickey, who has Down syndrome. They concentrated on all of the things typical parents concern themselves with such as the opportunity for their children to get a good education. Years later, as an adult, Joanne started a large "Learn to Swim" program for children with disabilities at the Somerville YMCA. In the late 1970s, she was honored by The Arc of Boston for her efforts and attended an awards ceremony where she learned more about the foun-



Ann Hegarty

ation of The Arc. Knowing her mother would be proud of the recognition she received for her work with people who faced the same challenges as her brother, she called her mother excitedly explaining all about The Arc of Boston. She told her that the organization was started by ten special women who worked together to ensure their children with special needs got a quality education. "I never knew that,"

Joanne said to her mother, "Did you?"

To that, her mother replied, "Yes, I was one of those ten women."

A flabbergasted Joanne reflected back on what she thought she knew of her mother and her life and realized what a remarkable woman Ann was and what a difference she had made not only for Mickey, but many others. Mickey got the edu-

cation his mother advocated for and worked in Boston, living in his own apartment. Ann passed away in January and Mickey, 72, is now in Wyoming near Joanne – an example of a life well lived.

Thank you to Tricia Nobis, who is married to Ann Hegarty's grand-nephew and has a 6-year-old son with Down syndrome, for forwarding this story. ■



Mickey Hegarty and great-grand nephew Blake

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

Temple Grandin to deliver keynote at The Arc's convention

Dr. Temple Grandin, this year's Image and Inclusion Award winner, will be the keynote speaker at The Arc's National Convention September 16-19 in Denver, CO. A noted animal scientist, author and subject of the award-winning HBO biopic starring Claire Danes, Dr. Grandin will speak about her accomplishments and living with autism. The film "Temple Grandin" recently won a Peabody Award and was recognized at the Emmy's and The Golden Globes.

We're pleased to welcome Dr. Grandin along with Dr. David Braddock, the force behind the "state of the states" assessment of state performance on issues important to the I/DD community at this year's plenary sessions. Plus, Convention attendees will be treated to an appearance from Lauren Potter of the hit FOX TV show



Dr. Temple Grandin

Glee. Those of you who attended the 2010 Convention in Orlando may remember Lauren's scene-stealing appearance there along with her co-star Robin Trocki as they received the first annual Image and Inclusion Award for

positive and accurate portrayals of I/DD in the media. Lauren will present the award to this year's recipient in Denver.

If you're interested in attending this year's Convention, register before August 5 and receive an early registration discount and discounted room rates. See the easy registration form inserted in this issue. Hammer Travel is our official travel sponsor offering customized, comprehensive travel arrangements for individuals with intellectual and developmental disabilities and their families to make it easy to come to Convention. Hammer Travel creates convenient travel packages which include lodging, Convention registration, arrangements to see area attractions, food and support staff. Visit www.hammertravel.org or call 1-877-345-8599 for more details. ■

update to "justice prevailed"



Joe Arridy, 1939

In the last issue of Empower, we reported on the posthumous pardon of Joe Arridy in Colorado, a man with developmental disabilities who was wrongly

convicted and executed for a crime he didn't commit. We failed to note that The Arc of the Pikes Peak Region was instrumental in organizing the grassroots support for Arridy's pardon, providing funds and support including securing a tombstone and arranging a funeral ceremony, collaborating with filmmakers working on bringing Ar-

ridy's story to the screen and staying in contact with the defense lawyer and state officials. Thanks to The Arc's intervention, Arridy's relatives are now comfortable with creating a special exhibit about the case in the Western History section of the Pueblo Public

Library. And, on May 18, The Arc of the Pikes Peak Region held a Day of Rally Seminar in Colorado Springs, hosting nearly everyone involved in winning the pardon in a celebration of this victory for intellectual and developmental disability advocates. ■

Attend the NCE Summer Leadership Institute August 5-7, Baltimore, MD

Challenging times call for creative leadership and it's time to get creative at the National Conference of Executives of The Arc's Summer Leadership Institute. Sessions will address the critical issues of Medicaid and employment and give you proven strategies for board governance, balancing life and work goals, building partnerships with families, increasing effectiveness and more. If you're a leader at a Chapter of The Arc or an NCE member, learn more and register by July 22 at www.ncearc.org. ■



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The Arc launches digital transition resources

In June, you'll be able to access information and resources designed to help families at a crucial time in the lives of individuals with intellectual and developmental disabilities – the transition from school to work or community life. A community resource database developed by The Arc's School-to-Community

Transition project will be valuable aid to individuals and their families and caregivers as well as professionals in the field, highlighting best practices and connecting people with needed resources. Visit www.thearc.org and check out National Initiatives to learn more when the database debuts in June. ■

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