



Monthly Memo
November, 2012

www.arcnm.org

(T) 505- 883-4630 ★ (F) 505-883-5564
3655 Carlisle Boulevard NE
Albuquerque, NM 87110-1644

The mission of The Arc of New Mexico is to improve the quality of life for individuals with developmental disabilities of all ages by advocating for equal opportunities and choices in where and how they learn, live, work, play and socialize. The Arc of New Mexico will promote self-determination, healthy families, effective community support systems and partnerships.

The Arc's 2013 Legislative Priorities

The Arc of New Mexico is a nationally affiliated, not-for-profit organization whose mission is to improve the quality of life of individuals with developmental disabilities of all ages by advocating for equal opportunities and choice in where and how they learn, live, work, play and socialize. The main office of The Arc is located in Albuquerque also has an office in Anthony and local chapters and part-time employees in other parts of the state.

Randy Costales is the Executive Director. The Arc provides state-funded guardianship services, lifetime planning, and training in areas such as legislative advocacy, alternatives to guardianship and, maneuvering through the state's service system for people with developmental disabilities and their families.

Maintain Services

Issue: Medicaid continues to be the crucial source of funding for people with disabilities that allows them to live in their communities with the supports and services they need. Any reduction in the state appropriation or even a failure to appropriate sufficient dollars will result in a loss of services and a corresponding reduction in the individual's quality of life. The Human Services Department has submitted its 1115 Medicaid waiver – Centennial Care. Issues may come up before the legislature regarding such things as expanding Medicaid eligibility to 138% of poverty as the federal law now requires.

Position: *Maintain current services for individuals with developmental disabilities and their families.*

Waiting List

Issue: Individuals with developmental disabilities continue to apply for services and then be placed on a waiting list (called the Centralized Registry by the Department of Health). People should not have to wait for services that are important to their ability to live and participate in their communities in a safe and fulfilling manner. 5500 or more individuals (un-served and

underserved) are on the waiting list for developmental disabilities services with a wait time of up to ten years.

Position:

1. *Protect the current DD Waiver appropriation and add new dollars to serve more people.*
2. *Protect the state general funded programs and add new dollars to serve more people.*

Medicaid Eligibility

Issue: New Mexico has one of the highest rates of individuals without any form of health insurance. This leads to higher insurance premiums for people who purchase health insurance and to more health care provided by the hospitals that is not reimbursed.

Position: *Support efforts to maintain the State Coverage Insurance program provided under Medicaid under the new Centennial Care waiver.*

Guardianship Services Funding

Issue: The funding for legal assistance and training for families seeking guardianship of a family member is not adequate to meet the need. Furthermore, the funding for corporate guardianship services no longer meets the need and a waiting list for services exists.

Position: *Support the Developmental Disabilities Planning Council's requested budget.*

Save the Date – 2013 Disability Rights Awareness Day

"Moving Forward Together for Disability Rights"

Monday, February 4 – Courtyard Marriott Santa Fe – One day seminar to learn the key issues

Tuesday, February 5 – Rally at the Capitol Rotunda (Speakers, Awards, Information Fair and visits with Legislators)

Join New Mexicans from across the State during the 2013 Legislative Session in Santa Fe. A hands-on community forum to advocate for your rights!

Sponsored by:

New Mexico Development Disabilities Planning Council
New Mexico Disabilities Coalition
The Arc of New Mexico
Disability Rights New Mexico
Governor's Commission on Disabilities
New Vistas – Center for Independent Living
Independent Living Resources Centers

A registration form is included with this memo. For more information contact Steve Scarton at The Arc of New Mexico at 505-883-4630 or 1-800-358-6493 or visit the web at www.arcnm.org.

We Are Waiting – End the DD Waiver Waiting List Campaign

Kayla Apodaca
Bernalillo County

My name is Theresa Apodaca. I am writing this story about my 22 year old daughter Kayla. Kayla was born with mental and physical disabilities. Kayla has suffered all of her life with chronic primary lymphedema, plus several other medical issues.

I have been a single mother for most of Kayla's life. Her father has never been in the picture. I was married for 6 years, and divorced now over 2 years. So I have been the only real caregiver to Kayla and will always be.

When Kayla was 9, her teacher and social worker recommended that I apply for the DD waiver. So in 1999 I applied for it and was told she was going to be put on the waiting list. So when Kayla turned 18, I had to go through legal guardianship. I had to check the status of her on the waiting list. To my surprise, I was told that she was not on the list or in the system. I explained to them that I had already applied in 1999. I was then told that there was a major system change in the states computers and many people were booted out. So I then reapplied in 2008. It will be 5 years in January, 2013 that she has been waiting. So that is a total of 14 years she has been waiting for the DD waiver.

To make a long story short, it has a major effect on both of our lives. I could not find anyone who could give her the proper medical diagnose, so I decided to go back to college to educate myself on what was happening with Kayla. After 21 years of pursuing and perseverance, I finally found a Dr. who diagnosed her with a rare congenital disorder called Hennekam Syndrome.

I recently graduated in Dec. 2012 with my BS. Unfortunately, I have not been able to find employment. I cannot even look for a minimum wage job because the cost of care is too expensive for me. I cannot afford to pay on that salary. In May of 2012, I lost my home of 20 yrs. I moved from Espanola to Albuquerque in search of a job. We are now Nov and I still have not found work. Due to the fact that Kayla is on general state funding, she is very limited to what services she may receive. It also did not work out with the people I was staying with. So now I find Kayla and me homeless.

If Kayla would have received her DD waiver when she was supposed to, I would have been able to get her the services she needed and not worry about having to pay someone for her care, which would have allowed me to find a minimum wage job to at least stay afloat. Also, maybe not be in the position we find ourselves in.

I have never been one to ask for help; maybe I should have pushed the issue with the DD waiver before I found Kayla and me in this predicament. The DD waiver would change our lives right NOW. It would give us back some stability and help us get back our lives. It would also help me pursue my dream in getting my PhD in Biomedical Research, so that I may help research my daughters syndrome and help millions others in the process.

If Kayla would have never been booted out of the system, our lives would be so different right now. She would be getting the help and services she deserves to be getting to make her the best that she can be. It would give me the peace of mind and the help that would give us back our lives.

Margarito Espinoza
Dona Ana County

My name is Yuriana Ortiz and I would like to introduce you to my son, Margarito Espinoza. He is on the DD Waiver Waiting List. He was placed on it the day he was born Margarito, or “Mayito” as he is lovingly referred to by his family, was born on April 8, 2008 at UNM in Albuquerque. He was a twin birth, and he currently resides in Anthony NM, along with 4 siblings and us, his parents.

Margarito was diagnosed at birth with Trisomy 8 syndrome, Pierre Robin syndrome, Dandy Walker syndrome, Hydrocephalus, Hydronephrosis, and a Cleft Palate. He was placed on a ventilator and has a feeding tube. Margarito’s life has not been easy from day one, but we have all worked hard together as a family to make life easier for him. Even though at times, the financial burden that has been placed on our family has been relentless and unforgiving. We do not have reliable transportation for Margarito nor is it equipped for a wheelchair, our many trips back and forth for treatment has taken a toll on our only family vehicle. We have no ramps for accessibility to our home, even though it is our mobile home the land is rented and the landlord stopped our construction of a ramp instead of the stairs to the front door. Now we have to carry him to the car and back into the home, the wheelchair remains outside because my back has given out after lifting and carrying not only Margarito but his chair also.

Currently he is not in school because it was recommended by his doctor that because he has to be intubated and fed through a tube it is better and safer to have a nurse with him constantly. Despite all his problems, Margarito is a happy, curious little boy. He finds pleasure in activating toys with lights and sounds and responds to familiar voices. Currently people on the DD Waiver waiting list can wait as long as 10 years before receiving services.



We are asking that the program be reassessed to possibly shorten the length of time so families and individuals like Margarito have a better chance at living as close to a normal life as possible. With all the strikes against them already changes in the system could alleviate the anxiety and frustration. We would be happy to discuss our concerns in more detail not only for our son but other New Mexicans with disabilities who face these real life issues.

Sincerely,
Yuriana Ortiz- Espinoza

Are you or a family member waiting for services? Please share your story. Call the Arc of New Mexico today at 505-883-4630 or Toll Free 1-800-358-6493. You can also email Carmen Garcia @ cgarcia@arcnm.org. Be sure to check out our website at www.arcnm.org.

*End the DD Waiver Waiting List Campaign funded by
The New Mexico Developmental Disabilities Planning Council*

Inclusion International Video Presentation

Last month The Arc National Convention was held in collaboration with Inclusion International. Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. For over forty years Inclusion International has been committed to the promotion of these human rights and the organization now represents over 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific.

The organization's Vision is a world where people with intellectual disabilities and their families can equally participate and be valued in all aspects of community life. Their Mission is with its member societies, Inclusion International acts as an agent for change on the basis of four main principles affecting the lives of people with an intellectual disability and their families:

- Inclusion in all aspects of everyday society
- Full citizenship which respects individual human rights responsibilities
- Self-determination in order to have control over the decisions affecting one's life
- Family support through adequate services and support networks to families with a disabled members.

Inclusion International has just uploaded a video presentation about their Global Report on Article 19 of the UN Convention: The Right to Live and be Included in the Community to:

- [our Facebook page](#)
- [our You Tube channel](#)
- [the Inclusion International website](#)

The presentation was shown at the National Convention and Global Forum, *Achieving Inclusion Across the Globe* in Washington DC last month.

Partners in Policymaking Recruiting Class of 2013

Twenty five years ago, the Minnesota Governor's Council on Developmental Disabilities created a ground-breaking, innovative training program called *Partners in Policymaking*[®] to teach parents and self-advocates the power of advocacy to change the way people with disabilities are supported, viewed, taught, live and work. During the past two decades, important issues have been confronted and dramatic changes have been made.

In the early 1990's, The Arc of New Mexico administered the program with funding from the New Mexico Developmental Disabilities Planning Council. The program proved to be a very positive, life-changing event for the individuals or Partners who participated and graduated from the program. Many remain active in making changes in their local communities and within the state. Although the program was very successful, the funding ended after three years.

Good news! In 2011 the University of New Mexico Center for Development and Disabilities reestablished the program in New Mexico. The mission of Partners in Policymaking is to create future leaders and advocates in the area of disabilities in New Mexico. The program utilizes the

nationally based curriculum that has been replicated all over the country and around the world. The program has graduated two classes and is now recruiting Partners for the class of 2013.

Partners are selected through an application process. Interested individuals must be able and willing to commit to attend seven, two-day training sessions in Albuquerque. Partners are given brief assignments between sessions and also participate in a small group project.

Applications are due by December 14, 2012. For more information contact Lauriann King at 505-272-5304 or laking@salud.nm.us.

Arc Executive Director Receives Award

The Arc of New Mexico Executive Director Randy Costales was one of two recipients of the 2012 Disability Advocacy Award presented at the Southwest Conference on Disability in October. Randy has been with The Arc since 1994 and became Executive Director in 2009.



Marilyn Martinez and Randy Costales

Be an Arc Ally - Donate to The Arc

The Arc of New Mexico is a statewide, non-profit agency that was born 56 years ago as a grassroots movement of families working vigilantly to create services for children and adults with disabilities who were being denied opportunities to receive an education, to work and to participate in their communities.

The Arc works on behalf of individuals with disabilities and their families every day to ensure that they have the support to participate in and contribute to their communities. The Arc serves as the Corporate Guardian for over 180 individuals, administers Special Needs Trusts for over 400 individuals and helps over 50 individuals with their Social Security Benefits in our Representative Payee Program. We also serve hundreds of people with disabilities and their families through our Self-Advocacy Programs and our Southern New Mexico Office located in Anthony, NM.

The Arc of New Mexico depends on public donations to sustain our work. You can make a one-time gift or a recurring gift. Make a donation now to support our mission to benefit all individuals with intellectual and developmental disabilities and their families in New Mexico.

A memorial gift is a beautiful and lasting tribute for a loved one or to a family as an expression of sympathy.

Family and friends can be recognized with a gift in their honor. This might be for a special occasion such as a birthday, anniversary, holiday, wedding, retirement, etc.

We Thank our 2012 Donors and Sponsors

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