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.

Can You Live Without Medicaid Services?

The Budget Control Act was enacted August 2, 2011 and outlines a three step process (see August Memo) to raise the debt ceiling by up to $2.8 trillion and reduce the deficit by $2.3 trillion over 10 years.

Between now and the end of the 2011 Entitlement Programs and disability related programs are very vulnerable – there are no protections for Medicaid, SSI, Social Security, Medicare, or other programs serving low-income people.

Think of it this way - major decisions are being made about you without you. Take a moment to imagine what your life or the life of your family member would be like without Medicaid and other services.

Justin Dart, the Father of the Americans with Disabilities Act once said, “Vote as if you life depends on it, because it does.” In this case let your Congressional Representative know how important these programs are to you and your family as if your life depends on it - because it really does. There is POWER in your story.

The Arc’s message:

- The budget cannot be balanced on the backs of people with disabilities
- Revenues must be a part of the solution
- Deep cuts in Medicaid cannot be tolerated and would result in harm to individuals and job loss in communities

Call to Action! For more information about The Arc’s “Don’t Cut Our Lifeline!” Campaign, go to www.thearc.org.
National Survey Reveals Urgent Unmet Needs

The Arc National Office conducted a groundbreaking survey of people with intellectual and developmental disabilities (I/DD) and discovered there are many urgent unmet needs for support keeping these individuals in the shadows of our society. A Report on Family and Individual Needs for Disability Supports (FINDS), 2011 was released in earlier this year detailing the survey’s top findings and outlining a broad call-to-action for the I/DD community and others who care about the rights of people with I/DD.

The following is an excerpt from the report. To read the entire report go to www.thearc.org.

A conservative estimate is that there are more than 1 million people with Intellectual and Developmental Disabilities (I/DD) waiting for services that may never come. ...Circumstances are imposing an enormous financial burden on families and have negative consequences for their family members with I/DD, but also for the families themselves and the communities in which they live.

• 47% of families report that they are paying more for care out of pocket.
• 21% of families report spending $1,000 or more per month for services and supports for their loved ones; an additional 23% spend $250 to $999 per month.
• For most families (63%), the money comes from the personal income or savings of the parent/caregiver or other family sources.
• 80% of families report that they don’t have enough money to pay for the support or care their loved one’s needs.
• 82% report problems balancing other family responsibilities (e.g., marriage, other children, housework).

The long term economic stability of families, as well as their ability to contribute to the economy as taxpayers and consumers of goods and services, is threatened as well. Income for people with intellectual and developmental disabilities remains low, with most people reporting that they live in poverty with Supplemental Security Income or SSI (33%) or Social Security (21%) as their only source of income; 25% have no income. Sixty percent (60%) rely on Medicaid for their health insurance; only 50% benefit from Medicaid funded home and community-based services.

• 82% of families report that their overall economic security is challenged.
• 81% of family care providers report that they don’t have time to attend to their personal needs.
• 73% report that they don’t have adequate savings for retirement.

And the future is uncertain. Nationally, more than 700,000 people with I/DD are living with caregivers who are 60 years or older. With 58% of family caregivers between the ages of 51 to 79, where will the individual with I/DD live and who will support them when their family members are no longer able to do so? Housing is unaffordable to individuals who have no outside income or who rely on safety net programs.
Developmental Disabilities Waiver Registration Update

It had been reported to The Arc and other advocates that individuals and families trying to sign up for the waiver were being told that they needed to wait for several months because forms were being redesigned and/or there were not enough staff to take applications. Representatives from the New Mexico Developmental Disabilities Planning Council (DDPC) met with Cathy Stevenson and Jennifer Thorne-Lehman in late August and learned that people are still permitted to apply for the waiver. However, due to the staff shortage applications are likely not going to be processed for two months or so. But the date of application will be stamped on the application when it arrives or on the date people registered by telephone.

Update on the Supports Intensity Scale Pilot Project

The Supports Intensity Scale (SIS) is reported as a valid and reliable assessment tool, specifically designed to measure the type of support, frequency of support, and intensity of support an individual needs to fully participate in community life. The SIS was designed primarily as a person centered planning process. Currently it is also being used in several states to inform and improve resource allocation decisions.

The information gathered from the SIS will provide the Developmental Disabilities Supports Division (DDSD) with the ability to fairly and equitably develop budgets to meet the needs of individuals with developmental disabilities in New Mexico.

The SIS Pilot Project (500 interviews) was completed on September 2, 2011. The first phase of the SIS implementation (400 mandatory interviews) started on August 15, 2011 in the Northwest Region. The implementation progress as of September is as follows:

- Northwest Region – Fifteen of twenty-four interviews completed.

- Southeast Region – All fifty-one interviews have been scheduled. Interviews started on August 31, 2011 and are expected to be completed by September 21, 2011.

- Northeast Region – All thirty-eight interviews have been scheduled. Interviews are to begin on September 19, 2011 and are expected to be completed by September 30, 2011.

- Metro Region – 239 interviews to be conducted. American Association on Intellectual and Developmental Disabilities (AAIDD) will conduct 131 interviews starting on September 26 and remaining 108 interviews to be conducted by DDSD.

- Southwest Region – Forty-eight interviews are to be completed between October 3 and October 13, 2011.

In October the SIS Subcommittee, of The Advisory Committee on Quality Supports for Individuals with Developmental Disabilities and Their Families (ACQ), will be meeting with DDSD staff and representative from the Human Services Research Institute (HSRI) to discuss the findings from the 500 interviews conducted during the Pilot Project.
The committee is working with DDSD staff to address two ongoing concerns – one concern is that individuals who have participated in the SIS receive a score but do not receive any feedback that can help them with future planning. To address this concern the committee will be reviewing examples of individual reports utilized by other states. The other concern is that some individuals have also indicated that the process has taken too long, was very strenuous and that the questions were too personal. The committee is working with DDSD staff to develop post-interview surveys – one for provider agency staff and another for other interview participants including individuals with disabilities, natural supports, paid staff and family members.

**The Arc’s 61st Annual Convention a Success!**

The 2011 Convention in Denver was a great success! Self advocates, volunteers, chapter staff, board members, and exhibitors had the opportunity to engage in conversations about the great things happening across our country. The 2011 Convention was more than an educational experience; it was an opportunity for advocates to network and find out what their colleagues are doing in communities throughout the nation. This year’s theme “Achieving New Heights” resonated through each session on our agenda. Together we are achieving new heights and finding new and innovative ways to grow as a movement, as an organization, and as individual advocates. For more information visit www.thearc.org.

**The Arc Featured in Time Magazine**

The September issue of Time Magazine includes a great article about The Arc. With more than 140,000 members affiliated through the more than 700 chapters, The Arc has been the lifeline for many of the 7 million people in the country with intellectual and developmental disabilities. It is the largest organization of and for people with I/DD and the ninth-largest charity federation in American, right behind United Way, with total revenue of $3.6 billion.

**Upcoming Events**

October 5-7 - The Southwest Conference on Disability at the Albuquerque Convention Center

October 27 – 30 – The National Indian Education Association 42nd Annual Convention and Trade Show at the Hyatt Regency Hotel. The event brings together Indian leaders, congressional representatives, and educators from throughout the United States and Canada. Forums and workshops will be held for educators to share concerns, ideas, and solutions to education-related issues that affect Native communities. Topics from early childhood through postsecondary education will be discussed. We hope to bring in the highest attendance ever at this year’s convention. For more information go to registration@niea.org.

March 22-24, 2012 - EPICS 9th Annual Family Leadership Academy, Sheraton Uptown Hotel. For more information visit www.epicsproject.org.

January 23-24, 2011 - Disability Rights Awareness Day, The Courtyard Marriott in Santa Fe and the State Capitol. Mark your calendars. No registration or program information available at this time.
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 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.