



THE

# Navigator

WINTER

Pilot Parents of Southern Arizona

Volume 18 Issue 4

Providing Information and Resources to Families and Professionals in Southern Arizona

## Congress Passes ABLE Act: Major Victory

### for Persons with Disabilities and Their Families

On December 16th, the U.S. Senate overwhelmingly passed the Achieving a Better Life Experience (ABLE) Act of 2014 by a vote of 76 to 16. First introduced in 2006, and subsequent sessions of Congress, the ABLE Act will allow people with disabilities (with an age of onset up to 26 years old) and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life. “Today marks a new day in our country’s understanding and support of people with disabilities and their families,” Michael Morris, National Disability Institute (NDI) Executive Director, said. “A major victory for the disability community, ABLE, for the very first time in our country’s policy on disability, recognizes that there are added costs to living with a disability.” He continued. “For far too long, federally imposed asset limits to remain eligible for critical public benefits have served as a roadblock toward greater financial independence for the millions of individuals living with a disability.”

NDI has long championed the ABLE Act as a critical strategy to providing a pathway to a better economic future for all people with disabilities. As the nation’s first nonprofit dedicated to improving the financial health and future of all people with disabilities, the organization has extensively documented and called attention to the daily reality and extra expenses associated with living with a disability, and the challenges of navigating the complex web of government rules to maintain public benefits eligibility. Prior to Senate consideration, and preceding passage by the U.S. House of Representatives (404 to 17), the ABLE Act was subject to protracted, bicameral negotiations that resulted in limiting access to ABLE accounts to individuals with a disability up to 26 years old. This amended version of the ABLE Act was necessary to quell budgetary concerns with the original version of the bill.

“While the bill is far from perfect, as is the vast majority of legislation, the ABLE Act lays the groundwork for greater financial independence and quality of life experience among people and families living with disabilities,” said Morris. “Although we are disappointed individuals over the age of 26 will be unable to access ABLE accounts at this time, please rest assured we will continue to work closely with Congress and the Obama Administration to identify, develop and open more economic pathways to all people with disabilities – including expanded access to ABLE accounts.” Concluded Morris, “In the meantime, however, we commend Congress for taking an important first step and call on President Obama to sign the ABLE Act into law without delay.”

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Pilot Parents of Southern Arizona 2600 N. Wyatt Drive, Tucson, AZ, Phone 324-3150

In recognition of the historic piece of legislation, the ABLE Act of 2014, NDI has created a list of 10 items about ABLE accounts that individuals with disabilities and their families should know. They are:

### **What is an ABLE account?**

ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, will be created as a result of the passage of the ABLE Act of 2014. Income earned by the accounts would not be taxed. Contributions to the account made by any person (the account beneficiary, family and friends) would not be tax deductible.

### **Why the need for ABLE accounts?**

Millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care and food and housing assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals to report more than \$2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor. For the first time in public policy, the ABLE Act recognizes the extra and significant costs of living with a disability. These include costs, related to raising a child with significant disabilities or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare.

For the first time, eligible individuals and families will be allowed to establish ABLE savings accounts that will not affect their eligibility for SSI, Medicaid and other public benefits. The legislation explains further that an ABLE account will, with private savings, “secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary’s employment and other sources.”

### **Am I eligible for an ABLE account?**

Passage of legislation is a result of a series of compromises. The final version of the ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you would still be eligible to open an ABLE account if you meet SSI criteria regarding significant functional limitations. The regulations to be written in 2015 by the Treasury Department will have to explain further the standard of proof and required medical documentation. You need not be under the age of 26 to be eligible for an ABLE account. You could be over the age of 26, but must have the documentation of disability that indicates age of onset before the age of 26.

*(Continued next page)*

### **Are there limits to how much money can be put in an ABLE account?**

The total annual contributions by all participating individuals, including family and friends, is \$14,000. The amount will be adjusted annually for inflation. Under current tax law, \$14,000 is the maximum amount that individuals can make as a gift to someone else and not pay taxes (gift tax exclusion). The total limit over time that could be made to an ABLE account will be subject to the individual state and their limit for education-related 529 savings accounts. Many states have set this limit at more than \$300,000 per plan. However, for individuals with disabilities who are recipients of SSI and Medicaid, the ABLE Act sets some further limitations. The first \$100,000 in ABLE accounts would be exempted from the SSI \$2,000 individual resource limit. If and when an ABLE account exceeds \$100,000, the beneficiary would be suspended from eligibility for SSI benefits and no longer receive that monthly income. However, the beneficiary would continue to be eligible for Medicaid. States would be able to recoup some expenses through Medicaid upon the death of the beneficiary.

### **Which expenses are allowed by ABLE accounts?**

A “qualified disability expense” means any expense related to the designated beneficiary as a result of living a life with disabilities. These include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services and other expenses which will be further described in regulations to be developed in 2015 by the Treasury Department.

### **Where do I go to open an ABLE account?**

Each state is responsible for establishing and operating an ABLE program. If a state should choose not to establish its own program, the state may choose to contract with another state to still offer its eligible individuals with significant disabilities the opportunity to open an ABLE account.

After President Obama signs the ABLE Act, the Secretary of the Department of Treasury will begin to develop regulations that will guide the states in terms of a) the information required to be presented to open an ABLE account; b) the documentation needed to meet the requirements of ABLE account eligibility for a person with a disability; and c) the definition details of “qualified disability expenses” and the documentation that will be needed for tax reporting. No accounts can be established until the regulations are finalized following a public comment period on proposed rules for program implementation. States will begin to accept applications to establish ABLE accounts before the end of 2015.

### **Can I have more than one ABLE account?**

No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.

### **Will states offer options to invest the savings contributed to an ABLE account?**

Like state 529 college savings plans, states are likely to offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated

*(Continued on page 5)*

# A LITTLE BIT OF THIS AND THAT.....



## NATIONAL AWARENESS MONTHS/DAYS

### January:

- National Birth Defects Prevention
- National Glaucoma Awareness Month
- Moebius Syndrome Awareness Jan. 24th
- Family Literacy Day Jan. 27th

### February :

- Rheumatoid Arthritis Awareness Day Feb. 2nd
- International Day of Women's Health Feb. 12th

- Rare Disease Day Feb. 28th

### March:

- World Down Syndrome Day Mar. 21st
- Purple Day for Epilepsy Mar. 26th
- National Kidney Month
- Multiple Sclerosis Education Month
- National Nutrition Month
- Trisomy Awareness Month
- Save Your Vision Month

## Surviving Toddler Mealtimes

Toddlerhood is exciting and challenging for parents. Have you found mealtimes challenging with your toddler? Perhaps your toddler has recently become a picky eater or is showing caution with the introduction of new foods. Come learn from the experts and help reduce mealtime stress and set yourself up for success.

### When:

Friday, February 13th or

Friday, April 10th or

Friday, June 12th

### Time:

10:00 AM - 12:00 PM

### Cost:

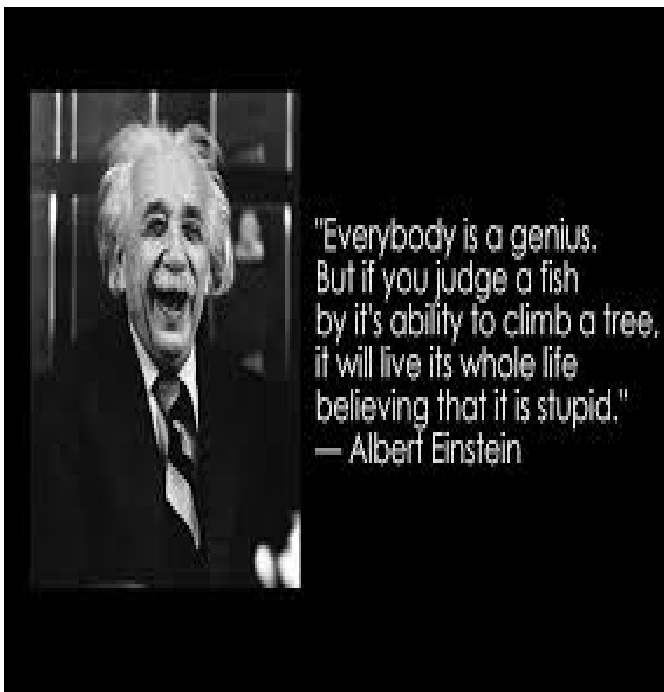
\$25

### Location:

1601 N Tucson Blvd, Suite 6

### RSVP:

Space is limited, please register at [mealt imeconnections.com](http://mealt imeconnections.com) to reserve your spot.





## An Evening with Jonathan Mooney

Fostering Positive Educational Experiences for ALL Students

Wednesday, January 28, 2015  
5:30 P.M. to 7:00 P.M.  
Doors open at 4:30 P.M.

Desert View High School  
4101 East Valencia Road  
Tucson, AZ 85706

Registration required: <http://tinyurl.com/jmooney0115>  
Light refreshments are available.

Jonathan Mooney is an author, learning activist, innovator, and international speaker. Mr. Mooney shares his passion, humor, and personal experience as an individual with a disability who didn't learn to read until he was 12 years old. Learners, family members, school personnel, and community members will be inspired and challenged to reimagine education for all students. To see a brief video about Jonathan's message OR to learn more about Jonathan, please go to <https://www.youtube.com/watch?v=yj1NhWOGShw>.

Sponsored by Raising Special Kids, Arizona Department of Education/Exceptional Student Services, Pima County School Superintendent, and Friends of the SunnyVal Student Leadership Conference.

Have you heard?  
There is **no coST** to attend  
this awesome presentation!






(Continued from page 3)

### **Will states offer options to invest the savings contributed to an ABLE account?**

Like state 529 college savings plans, states are likely to offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated beneficiaries are limited, by the ABLE Act, to change the way their money is invested in the account up to two times per year.

### **How many eligible individuals and families might benefit from establishing an ABLE account?**

There are 58 million individuals with disabilities in the United States. To meet the definition of significant disability required by the legislation to be eligible to establish an ABLE account, the conservative number would be approximately 10 percent of the larger group, or 5.8 million individuals and families. Further analysis is needed to understand more fully the size of this market and more about their needs for new savings and investment products.

### **How is an ABLE account different than a special needs or pooled trust?**

An ABLE Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program.

For more information on the ABLE Act, please read our [ABLE Act press release](#) or visit our [ABLE Act webpage](#). You can also watch our special "[Ten Things You Need to Know About ABLE Accounts](#)," YouTube video.

***Why am I always so tired?*** *I wish I had a nickel for each time I have heard that question over the past month or so. People blame the holiday season, the barometer, the rapid change in temperature, etc.. I think I know the real reason we are all so tired. I don't mean to be the harbinger of bad news, but parents of children with special needs have a rough life. Not unrewarding, not horrible, but absolutely difficult, filled with lots of stress and then the extra demands of managing your child with special needs in an already busy life. Add to this the holidays stressors: gift buying, what to buy for whom? How many people am I cooking for at Thanksgiving, Christmas, the remainder of my life? There always seem to be extra people around needing food during the holidays. Who ends up feeding them? You.*

*It isn't hard to see why we might be terminally tired. Hopefully by the end of January, our lives will return to normal and we will have the ability to take better care of ourselves again. In the off chance you are still exhausted then; here are some medical concerns you might ask your primary care to check out for you.*

(continued on page 8)



What does  
 “disabled” mean  
 when a man with  
 no legs can run  
 faster than most  
 people in the  
 world?



Join us for a very thought provoking film, reception and panel discussion sponsored by University of Arizona’s Sonoran UCEDD, Frances McClelland Institute and Disability Resource Center

January 30, 2015  
 4:45 PM – Hosted Reception  
 5:30 PM – *Fixed* Screening  
 6:30 PM – Panel Discussion

McClelland Park | 650 N. Park Avenue  
 Tucson, AZ

Panelists will include: Bijan Najafi, PhD, Associate Professor of Surgery & Director Interdisciplinary Consortium on Advanced Motion Performance; Chris Wenner, PhD, Clinical Psychologist & Health Behavior Consultant, El Rio Community Health Center, and others. Moderated by: Sue Kroeger, Ed.D, Director, Disability Resources & Adjunct Faculty, Disability and Psychoeducational Studies.

Please RSVP to this event by emailing Sacha Cueto at [sachac@email.arizona.edu](mailto:sachac@email.arizona.edu) or by phone at 520.626.0442.

# AZ Partners in Leadership

(an enhancement of the Partners in Policymaking program)

## Building Buddies – An Online Friendship Toolkit

The Building Buddies Facebook Page was the culminating project developed by six participants in the 2014 Partners in Policymaking training series, sponsored by Pilot Parents of Southern Arizona and funded by the Arizona Developmental Disabilities Planning Council and the Arizona Division of Developmental Disabilities. Partners in Policymaking, now called Partners in Leadership, is an educational advocacy training to develop citizen advocates that will create change through advocacy in various community efforts for the betterment for all who experience disability in their lives.

Our group was assigned to the 'Social Connections' topic at the start of the training series in January, 2014. This is obviously a very broad topic that can encompass many aspects of a person's life. We chose to focus on friendships and how we as parents can support and encourage them for our children. We all have children or grandchildren with special needs who have experienced difficulty in developing genuine friendships. We noticed that while we discovered a great deal of information about the importance of friendships, concrete guidance on how to help children foster friendships was lacking.

We decided to create a toolkit to provide direction for caregivers, primarily parents, to help sow the seeds of real friendships for their children. We gathered research from various sources and compiled the information in a single location, using a Facebook page to make it accessible and easily navigable. Embedded within the Facebook page is the toolkit document that provides resources, articles, templates, and many ideas of how to approach helping one's children develop friendships.

The group felt that the completed project was something that should be shared with a wider audience. We decided to submit a proposal to present it at the 2014 TASH National Annual Conference at one of the member's prompting. To our huge surprise, our proposal was accepted! It validated, for us, the importance of friendships for people with disabilities as a significant component of quality of life. Two group members attended the TASH conference in Washington DC December 3-6. The presentation was successful, as many of the attendees were very engaged in the topic and provided positive feedback. Discussion during the sessions reiterated the interest in the importance of facilitating social interaction and cultivation of friendship for people of all abilities, and the desire for ongoing access to information about this topic.

Our experience is a true demonstration that the action group projects can take on a life of their own and really have an impact. We hope that we have shown the potential for groups to gain national attention for their work. This would not have been possible without the support and dedication of the staff of Pilot Parents. We are grateful for the encouragement throughout the entire process. As a group, we feel fortunate to have been able to create and provide a needed resource to others. It is also accurate to state that through this experience we have seen that a small group of focused and dedicated people can make a difference in the world!

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*“I don't need easy. I just need possible.” Bethany Hamilton*

4th Annual African American  
Symposium on Disabilities

Friday, February 27, 2015

Desert Willow Conference Center  
4340 E. Cotton Center Boulevard, Ste. 100  
Phoenix, AZ 85040

Arizona Bridge to Independent Living (ABIL), in partnership with Arizona Center for Disability Law (ACDL), is hosting the 4th Annual African American Symposium on disabilities and would like you to join us! The Symposium mission is to reach out to individuals in underserved communities to provide information related to health care, employment, special education, legislative advocacy, etc.

For more information on continuing education units (CEU's), financial assistance (LEAP) <http://www.pilotparents.org/ppsa/programsandservices/Leap.aspx>, registration, etc. contact David Carey at [davidc@abil.org](mailto:davidc@abil.org) or by phone 602-443-0723.

**Staff Members:**

**Lynn Kallis**— Executive Director—Pilot Parents of Southern Arizona  
324-3151

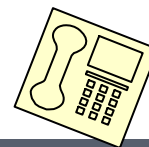
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**Amanda Heyser**— Education Coordinator  
324-3157

**Marianne Scott**— Partner's in Leadership Coordinator 324-3154

**Jo Ann Spencer**— Special Projects— Sibshop, Editor *The Navigator*, workshops.  
324-3153



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**THE *NAVIGATOR* IS PUBLISHED QUARTERLY. YOU MAY E-MAIL NOTICES, ARTICLES, ETC. TO [JOANN@PILOTPARENTS.ORG](mailto:JOANN@PILOTPARENTS.ORG), FAX THEM TO 520-324-3152 OR MAIL THEM TO: PPSA, 2600 N. WYATT DRIVE, TUCSON, AZ 85712 ATTN: JO ANN SPENCER, EDITOR, AT ANY TIME. SUBMISSIONS WILL BE USED BASED UPON SPACE AVAILABILITY AND WILL BE USED IF THE DATE OF THE ACTIVITY FALLS WITHIN OUR PUBLISHING SCHEDULE.**

*(Tired, continued from page 5)*

*Do you jump out of bed in the morning invigorated, ready to start the new day, or crawl out from under the covers already looking forward to going back to bed? Women tend to feel more tired than men and although it is often caused by an obvious or relatively minor problem, which is easy to fix, it may be the sign of something more serious.*

*The top 12 causes of fatigue:*

*Lack of sleep*

*Eating too little*

*Anemia*

*Underactive thyroid*

*Chronic fatigue syndrome (CFS)*

*Sleep apnea*

*Urinary tract infection (UTI) - if you are familiar with UTI's, they are normally very painful and cause increased need to use the restroom. That is not always the case; sometimes the only sign is fatigue.*

*Food intolerance*

*Diabetes*

*Heart disease*

*Depression*

*Glandular Fever ( I believe this is mononucleosis)*

*The good news about all of these afflictions is that they are curable. If caught in time by simple blood tests they can be treated. Take care of yourself and if any of the above symptoms are becoming part of your daily life; contact your doctor for a simple blood test to rule out anything serious.*



*Excerpts from WebMD by Siobhan Harris  
Why am I always so tired? Top 12 causes of fatigue.*



**Pilot Parents of Southern Arizona  
Upcoming workshops**

Estamos ofreciendo este taller *GRATIS*, no se lo pierda !

**Ponente: Dr. Fernando Armendariz**

**Fecha: Miercoles 21 de Enero, 2015 de  
6:00 a 8:00 pm**

**Lugar: Florence Manning Room, Children's Square and Compass**

Llame y Regístrese, no tiene costo pero hay cupo limitado!

Se proveerán refrescos

Regístrese con Pilot Parents al # 324-3150 o mande

correo electrónico a [joann@pilotparents.org](mailto:joann@pilotparents.org)

**El taller enseñara a los padres:**

Qué hacer cuando el hijo/hija hace berrinches?

- Como responder cuando no hace caso?
- Qué hacer para que coma bien?
- Como enseñarle a que se bañe sin rezongar
- Que hacer para que se levante

Como poderlo llevar a la tienda o a restaurants



# TRANSITION TO KINDERGARTEN

**January 21st, 2015**

**Bring your questions**

**12 to 1 pm**

**Bring your friends**

**Florence Manning Hall  
It's Free and Informative  
CCRS 2600 N. Wyatt Dr.  
Tucson, AZ 85719**

**Call Jo Ann**

**to save a seat**

**324-3153**



## SIBSHOP

**AGES 7 TO 12**

**Support for siblings of children with special needs. It's fun, its free and it is next Friday night January 16th from 6 to 8 at the Children's Clinics in the Flo-Mann room.**

**For more information or to register your child, please call 324-3153. Leave a message with your child's name, age and a phone number to reach you.**

**HOPE TO SEE YOU!!!!**