Stories include:

**What's Your Handicap?**
Adaptive Golf

**From Guns to Kayaks**
The Next Step in Adventure

**Lopex on Love**
A Lively Look at Relationships

**Rocky Point**
What's Accessible in Mexico?

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Message from the President & CEO

Justin Dart always reminded us to, “Get involved in politics as if your life depended upon it, because it does!”

These words ring so incredibly true and important today as ever before. The upcoming Presidential election in November is clear proof of that, but so too has been the 2016 session of the Arizona State Legislature. Several bills have been introduced, that if passed, would have widespread impact on the civil rights of people with disabilities.

One was SB 1284, a public accommodations bill that would have significantly compromised the civil rights of people with disabilities and weakened the Americans with Disabilities Act (ADA). Fortunately, it was pulled shortly after passage by the Senate Government Committee and will not move forward in this legislative session. SB1284 would have eliminated the rights of people with disabilities to obtain prompt and complete relief from the state courts by giving business owners 60 days to correct ADA violations before a lawsuit could be filed, thus creating incentives for businesses to be non-compliant to the ADA.

Another one, SB1166 (service animals) has created controversy and a divide in the disability community like no other bill in recent memory. Although we understand that some individuals who use service animals requested this bill in order to seek protection from non-disabled people who fraudulently claim to have a disability, the bill imposes a harsh solution that negatively impacts other people with disabilities who legitimately use service or assistance animals. Unfortunately, Legislators and other policy makers often view any person with a disability as an expert on disability rights. SB 1166 is a clear example of this, but it can lead to terrible results, such as businesses getting sued based on bad advice or lack of knowledge of the facts.

Additionally, some advocates don’t understand the differences in definition between service animal and assistance animal as defined by the ADA, the Fair Housing Act, and the Air Carrier Access Act. The ADA has a much narrower definition. If passed as is, SB1166 will result in businesses doing additional inquiry beyond the ADA, leading to a violation of our civil rights and subjecting us to civil and criminal penalties and fines. These penalties, if imposed upon a legitimate person with a disability using a service animal, are set at a higher standard than any regular “pet” owner would be subjected to unless the pet actually attacked a person.

People with disabilities should remember that as a community we are stronger when we act together. We can only remain effective in our advocacy if we are united before policy makers. Only then can we accomplish positive results for everyone in our community. This bill is not the answer to the problem of irresponsible pet owners. Many people with totally different disabilities use service or assistance animals and some are less obviously disabled than, say, a person who is blind using a guide dog.

We want our disability community to be proactive self-advocates and good stewards of our civil rights. In fact, I believe Arizona has some of the best advocates in the country. However, we also must be conscious of unintended consequences of our policy initiatives. If you have an issue that impacts public policy but are uncertain of its ramifications, please consider seeking advice from the Arizona Center for Disability Law or Ability360 prior to approaching the Legislature. Doing so can avoid these types of controversies.
Issue Four. We’ve come full circle…Happy Birthday to us! It’s been quite a ride. It’s only fitting that this edition seems to be all about journeys.

Our cover story on adaptive golf speaks to one golfer’s journey to reclaim who he’s always been. Yes, adaptive golf is here! Along with community partners, our sports and fitness team will soon offer this unique opportunity to hit the links.

We have two new sections this month: In “Lopex on Love” Ability360 staffer, Emily Lopex, takes us with her on her romantic journey. She’s asking that you share your own journeys, too.

The Creative Team traveled to Mexico (we told Phil it was for “work”) to explore the pros and cons of accessibility in Rocky Point. The pros far outweighed the cons, and we briefly considered the possibilities of never leaving the beach and working remotely from now on. You’ll see more from us as we “work” at various destination spots in the future.

Melissa Ann Santora introduces the Arizona Youth Leadership Forum; a group of young people well on their way to changing the face of disability empowerment.

Several of this issue’s stories are about people who journeyed to reclaim themselves after they acquired a disability. Nic Danger takes us kayaking and to the gun range with his new non-profit, The Next Step. Writer Brooke Brown introduces us to Isabella Mansfield, who expresses herself through her poetry and recently reclaimed a healthy lifestyle at the Ability360 Sports & Fitness Center. The Center was the impetus for Phoenix Heat Rugby team member, Jake Zunich’s move to Phoenix from New Mexico.

With the publication of this issue, it’s time to say goodbye to our interns, Andres Rosales and Yvette Mallari. We’re sad to see this part of our journey with them end, and we’re eager to see where their life paths take them. For this issue, Rosales takes us to an adaptive summer camp in the cool pines, Camp Tatiyee. Mallari chronicles Valerie Kappas’ uncharted path through the acquisition of three distinct disabilities and the adjustment tradeoffs that came with them.

As always, the inimitable Susan Webb offers her expert employment advice to those dealing with a work gap history as they navigate the application and interview process.

We also cover the Road to Rio for our Paralympians, the path one group of women are taking to empowerment – and invite you to join, and medical arts students becoming more disability sensitive as they represent the future of healthcare integration.

We’re glad you’re with us on this journey. Until next time... 😊
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AUG 6TH
5:10 PM

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 WHEELCHAIR ESCORT ASSISTANCE FOR ALL GAMES
 CLOSED CAPTIONING ON DBTV FOR ALL GAMES
FEATURED

10  Taking Risks with Nic Danger
   Your sense of adventure is calling!

14  Lopex on Love
   A fresh perspective in a column that welcomes dialogue

30  In the Swing of It: Adaptive Golf
   Adaptive programs to keep you swinging

40  Rocky Point Accessibility
   Take a trip south of the border!

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WRITER ANDRES ROSALES
Andres Rosales is a small-town kid who never learned how to write his biography. Instead, he spent his time watching music videos on YouTube. He’s a self-taught guitar player; participating in the occasional open mics; so he’s clearly come a long way. Andres is a sucker for breakfast burritos at midnight and intriguing discussions. Andres is a sophomore in ASU’s Walter Cronkite School of Journalism and Mass Communication.

WRITER KARA KAHNKE
Kara Kahnke has cerebral palsy. She is a community advocate and holds a bachelor’s in journalism and master’s in counseling from Arizona State University. She has volunteered at Ability360 since 2012, and received Ability360’s Mentor Match of the Year award because her mentor partnership accomplished her goal of learning to cook independently. She plans to become a Peer Mentor at Ability360 to inspire others to self-advocate and live as independently as possible.

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WRITER BROOKE BROWN
Brooke Brown loves to tell all types of stories that encourage others. She’s the author of The Little Butterfly Girl, a writer for Autumn Magazine, an actor in Theatre360, a public speaker and runs Brooke’s Butterfly Touch: Creative Storytelling Services, which strives to help others discover the power in sharing their own stories in order to cultivate hope, opportunities and understanding.

Letter to the Editor

Dear LivAbility,

I am interested in volunteering for Ability360. My background is marketing and journalism. Just curious if you are ever looking for volunteers or people to help you with your magazine?

Dear Reader,

In a single word? Yes!

LivAbility is always eager to showcase Arizona’s talent. We are looking for writers, photographers, graphic artists, editors and people willing to bring us cookies.

In all seriousness, you can contact us for our submission guidelines. We’re always open to your story ideas.
LivAbility is a quarterly publication of Ability360. President & CEO: Phil Pangrazio

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LivAbility is available as an accessible pdf online at www.Ability360.org/LivAbility. Large print and Braille versions are available upon request. Contact editor@ability360.org or call 602-296-0590.

How Are We Doing?

LivAbility Magazine is interested in your thoughts, comments, gripes, concerns, suggestions and ideas for future stories. Send us an email and we will do our best to keep improving with each edition.

Published "letters to the editor" will include first name, last initial and city, if known.

editor@ability360.org
“I was knocked down. When I propped myself up on my elbows, the guy was already pointing the gun at me.”

Seconds after he was shot he knew he was paralyzed. “I whispered a few words to God and the next thing I knew I heard a voice that said ‘do you need help?’”

He lost consciousness and woke up in the hospital a day later, not knowing how much time had passed.

After a recovery process described as “the darkest time of my life,” Nic Danger was aching to try something new. He saw an article headline that read: Try Scuba Diving.

He had never been scuba diving in his life, but he needed an adventure, a challenge.

“I stayed under water until the tank ran out of air,” Danger said.

It was the first time he felt a sense of freedom and independence since his injury. “All the weight from your bones is just released; it was the first time in a long time I felt normal again.”

Danger, 46, is now a Class A scuba diver, peer mentor, and president of a non-profit organization, which helps improve and empower the newly injured through education and recreation.

Danger started The Next Step in 2014 after seeing first-hand a need for peer mentoring for the newly injured. When Danger was going through his recovery he said there were other organizations out there, but not many reached out to him while he was in the hospital.

“When I went home they sent me with no pain medication or anything, and I lasted one day at the house.”

He was then admitted to a long-term care facility where he had to advocate for himself.
A year after his injury Danger developed a secondary condition, heterotopic ossification, where your body turns the soft tissue to bone. This required intricate surgery to allow him to have some range of motion. Danger contracted MRSA, a highly contagious bacterium. He spent two months in the hospital and was sent home with large, open wounds on both legs. He said the home nurses didn’t know how to deal with the severe wounds so he had to care for himself.

Danger started The Next Step “to reach people who are still in the hospital or have just come out.”

“My friend Corbin had three kayaks and we started scouting out places,” Danger explained. “I’m geared to taking people out and away from this area and getting them out into places where they see things they don’t normally see.”

Along with scheduled camping and kayaking adventures, The Next Step provides a shooting event each month, which started with just four people but has grown to 15 or more.

Sharon Malone participates in the target shooting events each month. She is a full-time wheelchair user due to spinal cord injury. “I didn’t shoot much before my injury, but I have grown to enjoy it. It’s great to be around people who are in the same position as me so I don’t feel as alone.”

Danger had no fear returning to shooting after being injured from a gunshot because “a gun doesn’t just fire; it’s whoever is behind it that did the wrong,” he said.

Michael VanWormer has an above-the-knee amputation and regularly attends the shooting events. VanWormer said, “The Next Step surrounds you with inspiring people; no one lets their injury or condition limit them.”

One of the goals of The Next Step is to change the public’s perception about people with disabilities. “You should see the looks on people’s faces when I’m at a dock and there’s my wheelchair and I’m climbing onto my jet ski,” Danger said.

The Next Step recently acquired its federal tax exempt number, the final step needed for it to become a nonprofit organization and accept tax-deductible donations. “I’ve been doing everything out of pocket,” Danger said. Friends have also helped.

Danger offers a peer mentoring program at various colleges and educates student occupational and physical therapists about spinal cord injury.

In the future, The Next Step hopes to buy jet skis and branch out to different recreational activities, such as camping.

Danger looks at being injured as not an ending but just a new way of life. Scuba diving helped him realize that. “I’m finding out that there’s not much I can’t do, even being paralyzed,” he said.
Beaubien didn’t start as a graphic designer. He came to 360 as a consumer. As Beaubien learned about services that could benefit him, he seized those opportunities. Through Vocational Rehabilitation and Ticket to Work, Beaubien obtained full-time employment in 2008 as the Advocacy Program Aide. His ambitious attitude led him to attend the Art Institute of Phoenix while working full time, and in 2014, he earned a bachelor’s degree in Graphic and Web design. He also worked his way into the marketing department.

“Ability360 has changed me.” Beaubien describes himself as typical, not too different from his peers. “I see now that anyone can reach their goals with or without disabilities,” John says.

“Put most of your focus on one goal, don’t give up when roadblocks present themselves and seek help when needed.”

He and his wife Kelly own a home and have two sons. His passion for healthy cooking is legendary on the Ability360 campus.
Welcome to the newest edition of *LivAbility*

*LivAbility* is a magazine for people with disabilities in Arizona. The free quarterly publication of Ability360 contains articles that promote an active, fulfilling lifestyle for every ability.

*LivAbility* currently mails to 2,600 individuals and an additional 3,400 copies are distributed at various locations, predominately in Maricopa County.

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One of my biggest frustrations with articles on dating from the perspective of a person with a disability is that one person cannot possibly speak for an entire community, particularly one as diverse as ours. I see this ongoing column as the catalyst for others to consume and then respond from their perspectives.

by Emily Lopex

I remember the first time I had a crush on a boy. I was eight. He had dark eyes, curly hair that swept across his forehead and a smile that made me swoon.

I decided I must have him, and did what I do best; I wrote passionately about my desire to meet him on the playground and marry him under the monkey bars. I drew a map from the classroom to the playground and placed it inside his desk drawer.

As any eight-year-old boy would be, he was perturbed by being pursued by a girl. Particularly a little girl with braces on her leg and arm. His face was a permanent shade of red for the remainder of the year as our classmates teased him for being the object of my affection.

He never did come to the playground that day, but that didn’t faze me much. I moved on to other interests and other boys, my audacity growing each time.

I've had cerebral palsy my entire life, but despite its obstacles, both social and environmental, it never quite registered to me that the world saw me differently until I started liking boys. To be fair, the construct I had built for myself that said “I can live the life I want in spite of my disability” came crashing down at thirteen, when I heard a boy I liked speak fondly of my beauty and character then say he could never date someone with a disability. And if at any point I was tempted to believe that his opinion was the exception and not the norm, men would continue to come in and out of my life voicing the same opinion for years to come.

The hardest lesson I've had to learn is that I cannot advocate my way into the heart of another.

Such a buzzkill, right? To spend a lifetime advocating for my right to attend mainstream education, to learn to drive, to simply be allowed to be fully human, only to discover that dating and romantic relationships is the one area of my life I can’t create on my own. The person
sitting across from me either accepts all of who I am or he doesn’t. No amount of advocacy can make another person date you, nor should you want it to. Learning to rest in the tension of what it means to both fight for the life I want as a young woman with a disability and also understand that there are parts of my life that I cannot force to happen in the timing I want it to happen is a process I am still learning to master.

My hope with this ongoing column is that by sharing parts of my story, sometimes humorous and other times in the throes of disappointment, a dialogue is started. I want - we at Ability360 want - to hear your stories of love and heartache, the lessons we all have to learn in the process of becoming who we are meant to be. This is the “360” of Ability360. One of my biggest frustrations with articles on dating from the perspective of a person with a disability is that one person cannot possibly speak for an entire community, particularly one as diverse as ours. I see this ongoing column as the catalyst for others to consume and then respond from their perspectives.

May we be honest and compassionate in how we respond to one another, never ceasing to listen or learn and have the humility to admit we have more to gain from each other than we do from criticizing the process someone else is going through.

Happy responding, fellow 360 Humans! 🌼

Reach Emily at AskEmily@ability360.org with your stories of love and life.
In the “Breaking Bad” spin-off “Better Call Saul”, a brilliant lawyer named Chuck refuses to leave his house due to his sensitivity to electricity. Saul takes care of Chuck while others write him off as eccentric. Hollywood isn’t known for accurate portrayals of well, anything, and disabilities are no exception. What rings true is the skepticism that surrounds Chuck’s electrical sensitivity, because his disability is invisible.

Environmental disabilities were invisible to me too, until I met Valerie Kappas, whose experiences echo Chuck’s. Kappas, an artist and former small business owner in Mesa, uses Ability360’s Home Care Services.

Before I even set foot on Kappas’ doorstep, I contacted Mary Lamielle, founder and executive director of the National Center for Environmental Health Strategies. Chemically sensitive since her mid-20s, she devoted over three decades to researching and advocating for those with environmental disabilities.

“I was very sick, but I was very aware,” she said.

A major complication for those with environmental disabilities is that the medical field has yet to find a successful provocation study—proof that the environment is the true cause of the symptoms.

Also, environmental sensitivities go by seemingly dozens of acronyms, EHS (electrical hypersensitivity) and MCS (multiple chemical sensitivity) being the most popular. Lamielle states that these terms are loaded. She explains that some in the community find these labels demeaning and prefer environmental sensitivities or intolerances.

“Environmental sensitivities tend to be put in the allergy category,” she said. “So when researchers test this, they find nothing, and they say ‘this does not exist’ because it’s not an allergy. It’s not an allergy, but it does exist. You’re not going to find anything if you have your eyes shut or your mind shut.”

Before meeting Kappas, resources suggested I wash my clothes with white vinegar and avoid all scented products. I followed these instructions to a T, yet she told me I was still fragrant. It can take up to a week for someone to completely neutralize.

“Some people are very attached to their fragrances,” Kappas said. “I have to ask caregivers to make lifestyle changes, and some people are willing to do that and some people aren’t. Your home is supposed to be your safe environment where you can recuperate and avoid that kind of thing.”

Due to the exposure risk imposed by my battery-powered camera, I used a lens that allowed me to take photos of her from a distance. She explained how isolated environmental disabilities left her.

She requires caregivers and used a power chair due to a C5-6 spinal injury. Afterwards, she developed chemical sensitivity. Her chemical sensitivity symptoms range from nausea to sharp lung pain. She stopped...
painting, and never leaves the house without her own oxygen and a ceramic mask.

To reduce her exposure, she worked, socialized, and created art via computer, which gave her access to the world within a controlled environment.

However, Kappas later developed electrical sensitivity, and her solutions for one disability became problems for another. Her power chair and computer made her ill, causing headaches and fatigue. Giving those up left her world a lot smaller.

When speaking about the tradeoffs caused by exposure to her electrical devices, Kappas said, “For me, personally, the electrical sensitivity is worse than the chemical sensitivity.”

“These containers were filled with flowers and food plants,” she motioned to the scattered pots around her backyard, most of them empty. “Now in my manual chair, I can’t get out of the house by myself. I can’t open the door and get on the ramp by myself. I would rather be outdoors than indoors. So that’s been really radical for me.”

She heard of “Better Call Saul” through a nighttime caregiver. Kappas wondered, “Is it going to make us look crazy or are they going to take it seriously?”

Many caregivers do not understand the limitations her disability imposes.

“You get tired of asking people to change their lifestyle,” she said, knowing that her health worsened the last time she tried pushing her limits.

“If I’d stayed off the computer more, I’d probably at this point still be able to do more.”

Kappas’ artwork hangs in her home, a reminder of the days before her chemical sensitivity ended her painting career.

Her home holds a miniature forest of air-purifying plants next to a table jam-packed with no-longer-used paintbrushes. Her art work, including a self-portrait and vibrantly painted palm tree bark, still hangs on purple walls.

Despite electrical sensitivity, she’s determined to keep a white-knuckled grip on the fleeting digital world no matter what, even risking her health just to keep up with the latest viral video.

While most of the battle is self-advocacy and awareness, there is hope for broader understanding. Documentaries...
like "The Human Experiment" and even TV shows like "Better Call Saul" are giving attention to a once-hidden condition. Studies are focusing on the link between genetics and increased chances of developing an environmental sensitivity. The US Access Board's Indoor Environmental Quality Project Report explains and proposes solutions for healthier indoor environments, and centers like Ability360 are scent-free. Progress is slow, but advocacy continues toward giving invisible disabilities the visibility they deserve.

Suspect you have an environmental sensitivity?

Dr. Claudia S. Miller, an allergist and immunologist, offers the Quick Environmental Exposure and Sensitivity Inventory (QEEIS), which screens for environmental intolerances. If there is a pattern, individuals can take the results to their physician.

www.chemicalexposures.org

Lamielle suggests:

- Buy organic foods
- Make a neutral space in order to test different exposures
- Keep a log

Avoidance is critical, as a symptom can be caused by any number of triggers.

Book Review

Becoming MySelf: A Soul Journey with Chronic Illness & Disability

Author: Darrell Lynn Jones
Review by Amina Donna Kruck, Ability360

As a person who has lived with chronic illness most of my life, I found Jones' book entertaining and validating. Jones worked within the context of the disability civil rights movement while having several chronic illnesses that affected her energy, memory and ability to think. Yet, it took her years to think about her chronic health issues as something that needed to be accommodated. Like many of us with chronic conditions and invisible disabilities, she describes so well her struggle with the stigma she experienced, within the disability community and her own family, and the effect it had on her self-image and self-care.

The book describes a journey from feeling like a failure for not being able to cure chronic health issues and a self-image as "damaged goods" (my words) to accepting her health issues as just another way for a soul to experience life in its unique way. For years, Jones tried a myriad of traditional and alternative medicine and spiritual and metaphysical practices in an effort to be "well". She takes us through her process of discovered self-acceptance and learning to trust her inner guidance. This acceptance and trust brought back joy in living and learning to take realistic care of herself, to seeing her "self" in a larger perspective, which she calls a soul. She expresses the best contradiction to ableism and negative stereotypes about disabilities is to see each of us as a unique expression of the divine.

Jones is a civil rights activist who writes in a sometimes humorous and often matter-of-fact style, sharing practical solutions to her situation that inspired me to continue to assess my own life and priorities so that I can live the best life possible with this pesky and divine human body.

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**Q&A**

**GAP IN WORK HISTORY**

**How Do I Explain It?**

**JS (Job Seeker):** I have not worked in several years, but now I am ready to get back in the workforce. During a recent interview, the employer asked about the gap in my work history, so I told her I was recovering from a disability. I never heard back. Are they discriminating against me because of my disability? Isn’t that against the law?

**EA (Employment Advisor):** Wow! That is a complicated question, but not unusual.

1. Never answer this question by disclosing that you have a disability. There are many reasons for a gap in work history. You could be building a house, raising children, caring for an elderly parent, and yes, recovering from a disability.

2. Your answer should always be, “I was handling personal matters, but here is how I have kept my skills current.” Your disability is a personal matter and does not answer what they really want to know. Are your skills current? How do they know you can really do this job?

3. Discriminating against you because you have a disability is against the law and violates the Americans with Disabilities Act of 1990 (P.L. 101-336). For more information on Disability Disclosure, please visit www.ability360.org and click on the employment page. View the 30-minute webinar on this topic.

**JS:** Most of the time, I never hear back on my application. Could that be because of the gap? How can I address it on my application?

**EA:** There are many reasons you will not hear back. The gap in work history is one reason. Your resume does not include much flexibility to overcome the gap other than the techniques discussed in the answer to the next question. However, the cover letter gives you the opportunity to explain it. Even if the application does not ask for a cover letter, you should include one on the same document upload as your resume. A cover letter should never be more than four short paragraphs on one sheet of paper. The third paragraph is a good place to explain the gap by mentioning you were handling personal matters, but you have kept your skills current by . . . just as in the first question. But make no mention of your disability.
1. According to the US Department of Labor, 82% of jobs in the US are full-time jobs. Although it is certainly understandable to be concerned about your ability to work full time, just remember you are significantly reducing your job opportunities with a part-time mindset.

2. Unfortunately, many people with disabilities make the assumption that the mental and physical exhaustion they experience when returning to work is because of the disability. In fact, anyone who has not worked in a long time experiences this. Knowing, understanding, and expecting this helps to overcome it. A guiding principle is it takes 90 days working full time before you know you can handle it.

3. Even though you have not worked in a long time, it is likely you have been active in other ways. It is not practical to return to work and attempt to continue doing everything you are doing now. You need to adjust your lifestyle to accommodate a work schedule. The job becomes the priority. It is important that you inform family, friends, and others who have expectations of you that you will not be available anymore and alternatives must be found.

**Good luck with your job search!** ☺

---

*If you have questions or comments, please e-mail Susan Webb at susanw@ability360.org*

*By Susan Webb, VP of Employment, Ability360*
Sweat, exhaustion and focus play on Jake Zunich’s face. He viciously bites down on his rubber gloves and pulls them up higher onto his hands and enters the game for the Phoenix Heat Wheelchair Rugby team. Born in the small mining town of Silver City, New Mexico, Zunich grew up an only child with two loving and supporting parents. He was All-State in baseball and football and ultimately received a baseball scholarship to El Paso Community College in Texas in 2010.

“I had a partial scholarship offer to play baseball for the University of New Mexico at shortstop and third base,” Zunich said. “Some scouts at the pro-level were looking at me and suggested I go the junior college route instead.” Zunich took their advice and had a successful freshman year at El Paso. He was looking forward to his future baseball career.

That summer, Zunich and his friends were swimming at the San Francisco River in Arizona. “It was just kind of a yearly thing with a group of my friends, a tradition,” Zunich said. He collided with a rock due to a shallow dive, sustaining a C6 spinal cord injury. “I guess my momentum was enough to cause the break.”

Zunich was flown by helicopter to an ICU in Tucson, AZ. Two weeks later he was moved by ambulance to St. Joseph’s Hospital. “I ended up getting some forty staples and eighty stiches in my head;” Zunich said.

“I was a college athlete. I was used to getting up at 6 a.m. and going to a workout, class, and practice,” Zunich said. “Having to change from being so busy and active to slowing everything down was a huge change.”

Zunich had a hard time adjusting to his new way of life. Simple things like zipping jackets and tying his shoes were now daily challenges.

“Not being able to touch your fingers together or hold your arms against gravity was a real eye opener,” Zunich said. “Being an athlete, my mindset was I’m not going to let this hold me back or define who I am.”

Zunich found his determination and support through his parents. He credits them as his motivation and drive to live his life to the fullest.

“Every time I wanted to give up with something, my parents were there to tell me that I can’t let this beat me,” Zunich said.

He also found strength in role models who assisted in his adjustment to disability, including teammate, Joe Delagrave.
Delagrave is a starter for the Phoenix Heat, and a member of the United States National Rugby team, which has Paralympic aspirations.

“The first time I met Jake was when I was mentoring patients at St. Joseph’s and we ended up having similar stories in that we were both hurt at nineteen and athletic before,” Delagrave said.

“To see him transition from rehab, to living independently, to becoming a very good rugby player says a lot about who he is as a person.”

Zunich’s future goals include making the United States National team and going back to school to obtain his associate’s degree. He wants to pursue sports medicine one day.

The Phoenix Heat are preparing for Nationals, which take place April 22nd to the 24th at the University of Houston.

Photo by Loren Worthington
Arizona Prepares Future Leaders

by Melissa Ann Santora

Arizona Youth Leadership Forum (AZYLF) for Students and Transitioning Young Adults Who Have Disabilities is an innovative, 6-day conference, for students and young adults who have disabilities, as they prepare for and experience transition to adulthood. Designed to foster personal growth through self-discovery, AZYLF provides experiential learning opportunities to assist each individual as they identify and embrace their strengths and gifts, in conjunction with planning for their future.

Now in its third year, AZYLF 2016 will be held at the Arizona State University campus in Phoenix Arizona, June 12-17, 2016, and is a collaborative effort between Arizona Statewide Independent Living Council, Arizona Rehabilitation Services Administration, and other invested partner organizations. The dynamic environment of AZYLF focuses on leadership development, career exploration, effective advocacy, and empowerment.

AZYLF invests in our most precious resource, the youth who will transform our tomorrows.
through heightened awareness of disability history and culture. AZYLF brings together up to 25 youth who have disabilities from across Arizona, who are selected through a competitive application process. The conference successfully integrates youth, who are referred to as Delegates, who represent the diversity of disability and culture in Arizona. Although undeniably purposeful and relevant, the true value of AZYLF is not found in a workbook or in the words of an accomplished presenter; it is found in the climate of trust, mutual respect, and absolute acceptance, which allow youth to be themselves, to be heard, and to be changed.

AZYLF invests in our most precious resource, the youth who will transform our tomorrows, and to support that investment, AZYLF has established an active Alumni Association, governed by an Executive Committee of eight.

“AZYLF is a life-changing experience that has given 43 young people, including me, the opportunity to realize that we are meant to be more than we imagined,” said Audra Paletta, AZYLF Alumni Association Chair. “Our capabilities are enormous when we look beyond the bubble we have lived in during our lives. AZYLF has helped us to burst that bubble. It gave me courage, and I now know what I want from the world. I just gotta be unafraid to grab it,” she expressed.

AZYLF Alumni have been engaged in every step of the planning for AZYLF 2016, and are working diligently on Delegate recruitment and resource development efforts. AZYLF Alumni have much to offer, and much more to share. Look for them to do just that in “YouthAbility”, a new feature of LivAbility Magazine.

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www.azylf.org

Melissa Ann Santora, Director of Administration
Statewide Independent Living Council

Under the creative coordination of Ms. Santora, this year will mark the third Youth Leadership Forum in Arizona.
In this profile, we are introduced to a caregiver and consumer whose unique friendship blossomed despite one...or two...generation gaps.

It is a sunny, cool afternoon in San Tan Valley. I am greeted at the front door by Maria, one of Ability360’s Home Care Services caregivers. As I open the door, “Rocky”, a Chipin Applehead Chihuahua, darts out into the front yard. Before introductions can be made, we must corral this little flying squirrel back into the home. More about Rocky’s story later. Alyssa and her mother, Kati, both greet me and we all make our way to the dining area to talk. Maria currently cares for Alyssa, who is 17 years old.

Alyssa’s journey has not been an easy one. Born with Spina Bifida (“open spine” means that the spine is open like a zipper that doesn’t zip closed all the way), Alyssa had issues with Type II Arnold-Chiari malformation, tethered cord, hydrocephalus, syringomyelia and kidney-related issues, including high blood pressure and hydronephrosis. Alyssa received a tracheostomy at just three months of age. Prescribed steroids wreaked havoc on Alyssa’s already weakened immune system. Alyssa sees many specialists, and in addition to Maria, Alyssa has a part-time nurse that comes to the home.

“There’s something about her essence,” Maria tells me matter-of-factly. Maria has been officially caring for Alyssa for two years now. Maria ran her own daycare for 21 years. She met Alyssa through Alyssa’s grandmother, with whom she was conducting wellness classes. Alyssa’s grandmother was a nurse for 42 years and Maria, a Wisconsin native, is a naturopath, using nutrition and essential oils in a holistic manner to promote healing. Maria had suggested peppermint oil for Alyssa’s headaches. In addition, Maria discovered that Alyssa was mainly being fed sugar, with minimal nutrition. Maria and Kati replaced the tube-feeding formulas with natural options, which have led to Alyssa having gone a year without any hospitalizations. Maria continues to massage essential oils on Alyssa’s temples, which helps prevent her headaches.

Maria and Alyssa hit it off right from the start. They began Face Timing with each other within 24 hours of

She has undergone 14 plus surgeries throughout her short life, including three on her brain stem.

In 2010, Alyssa underwent Chiari decompression surgery on her brainstem to relieve tissue crowding and pressure. The brain stem connects the cerebrum with the spinal cord and controls our most vital autonomic activities: heart rate; breathing; digestion; arousal; alertness and swallowing. Prior to this surgery, from age 2 to 12, Alyssa had walked with a walker. Her voice, leg function and her ability to swallow were all compromised afterward. Alyssa had to get a permanent feeding tube. Brain swelling caused additional issues.
meeting, Alyssa asked Maria to teach her to paint. The duo now spends a lot of time painting together. Alyssa is quite the talented artist. She has sold several of her paintings. Kati brings three of Alyssa’s recent pieces of art for me to see. They’re stunning. One of the paintings has a Green Bay Packers theme. This has been Alyssa’s favorite NFL team way before her connection with Maria, who hails from Wisconsin.

This brings us back to Rocky. Maria bought Rocky for the two of them to share. Maria takes responsibility for feeding and cleaning up after the puppy, and he goes home with her. Rocky will ride on Alyssa’s chair with her when they go for walks in the neighborhood. He licks her cheek and is completely full of adorable mischief.

Alyssa is surrounded by love and support via a blended family. She attends school both in person and online. She is co-editor of her school’s newspaper. Since Alyssa’s voice is very weak, she is excited that she will soon be receiving assistive technology computer equipment from Northern Arizona University. This will enable Alyssa to work more independently on the computer at home.

Maria and Alyssa playfully tease each other throughout their time together. Maria will comb Alyssa’s hair, dress her and “water her” (tube-feeding). They both have a love for music, and Alyssa laughs out loud when Maria tells me that she does the chicken dance, Macarena and the cupid shuffle all for Alyssa’s amusement. Maria and Alyssa do crafts together, whether making jewelry, sand art or painting. They are often engaged in a collaborative activity when together.

Kati speaks to her daughter’s strength in the face of daily adversity and how it’s a privilege to be her mother. Kati states it is important to keep Alyssa’s mind occupied, so as to keep negative thoughts at bay and maintain her normally upbeat, positive attitude. Kati asserts that Alyssa is the happiest kid in the house and that she is generous toward others. She gives great advice and is the first to reach out to family members in other states and keep everyone connected. Maria states that Alyssa reasons conscientiously like a 35 year old yet can have fun like a 5 year old.

When asked what the connection between Alyssa and Maria has meant to her, Kati replies, “So much. Alyssa was missing something.” As her mother, Kati fulfilled her role completely. Yet, Kati knew that Alyssa needed someone else with whom to talk and do things.

“I literally prayed for someone for her. I felt like I needed help cheering her on. It’s [their relationship] meant the world to me.”

Maria refers to her relationship with Alyssa as a “17 year old with a 50-year old BFF”. It’s certainly a unique pairing, one that is obviously cherished by both Maria and Alyssa. Maria is certainly much more than a caregiver, providing respite for Kati and companionship and care for Alyssa. Maria is first and foremost a friend and family member, trusted and embraced as only a true friend can be.

“Alyssa was missing something.”
New Fitness Trends to Rejuvenate Your Routine

by Nathan Skotak, Exercise Science Intern, Ability360 Sports & Fitness Center

It’s that time of the year… when those who made New Year’s resolutions to improve their health or fitness levels tend to disappear from the gym. Time becomes an excuse for veering off your consistent exercise schedule. Maybe you just need something new to kick start your return to activity. These fitness trends of 2016 are all great ways to switch gears and steer yourself back to your goals.

High Intensity Interval Training (HIIT)

HIIT training involves short intervals of high intensity exercise followed by a recovery interval. A popular example of HIIT is Tabata. A typical Tabata routine includes 8 sets of one exercise. Each set requires 20 seconds of intense work followed by 10 seconds of rest.

Ability360 Sports & Fitness Center offers Tabata, Core Tabata, F.I.T. (Fitness Intensity Training), and a boot camp class, which all utilize HIIT to take fitness to a new level.

Rowing

More people are choosing rowing as physical activity, or even as a warm up before their exercise program. This activity involves a full body movement to pull a modified rowing handle toward the upper body. This repetitive movement results in both a resistance and cardio-respiratory workout. Ability360 Sports & Fitness Center is never short of rowing machines and has multiple adaptive seats.
Fitness Trackers
Over the last couple years, you might have noticed the increase of fancy bracelets being worn on the wrists of a variety of people. These bands aren’t just bracelets; they’re most likely a fitness tracker. Two popular fitness trackers are Fitbit and Nike+ Fuelband. Fitness trackers have the ability to track heart rate, calories burned, distance covered, as well as, monitor one’s sleep. Nike+ Fuelband has a feature to measure arm and wrist movements such as pushing a chair. This gadget is not mandatory, but may give you the extra motivation you need to stay active.

Yoga
Yoga’s popularity and benefits have transcended centuries. This activity has outlasted many fitness trends due to its myriad mental and physical benefits. Those looking for a way to relax and expand their mind should try Yoga Nidra, a class that places attendees in a unique state of mind. Other Yoga classes will include the mental benefits but place focus on increasing range of motion by stretching. Stretch yourself and try Yoga or Yoga Nidra at Ability360 Sports & Fitness Center.

Innovative equipment
Krankcycles™ are hand spin cycling machines. These hand cycles have independent crank arms, which can adjust to cycle in both directions, and the ability to increase and decrease resistance with a quick turn. These bikes are available on the fitness floor and in group fitness classes at Ability360 Sports & Fitness Center.

Ability360 fitness class schedule available online at www.Ability360.org or call (602) 386-4566
“So, you were a golfer?”

“I am a golfer.” Bob Larson corrected gently, out on the Encanto 9-hole course. Less than a month into recovery due to a spinal cord injury, Bob was enjoying a sunny day on the links as part of the Barrow Neurorehabilitation monthly golf clinic at St. Joseph’s Hospital. He’s still wearing his body brace, which impedes his swing. But, on a beautiful spring day on one of Phoenix Metro’s more than 200 golf courses, he was in the zone.

Golf is more than a sport. It’s an identity, a way of life. With Ability360’s Adaptive Golf equipment and local programs, golf can still be your game.
Tim Surry sinks a putt from his Stand Up and Play chair while Jason Graber, Nick Pryor and Sara Callagy look on.
If you’re ready to take a swing, this is what you need to know.

1. Carts & Chairs: Stand Up and Play golf units serve as power wheelchairs that carry you over the course and raise you like a standing frame for your swing. Ability360 has three units available. Solo Rider units are single-rider golf carts with a swing-out seat to elevate the golfer for a full swing. Ability360 has two units. Depending on your ability, a person can use one or the other. In some instances, people play out of their everyday wheelchair.

2. Clubs: Ability360 has clubs available for beginners to learn the sport. Seated golfers can typically use a standard set of clubs. Clubs can be customized to accommodate a modified swing.

3. Courses: Adaptive carts and chairs can be used at most courses with permission of the course. Currently, Ability360 is partnering with Longbow Golf Club in the East Valley and Encanto Golf Course in Midtown Phoenix for instruction and individual play. Calling ahead to clubs unfamiliar with this equipment is recommended.

4. Monthly golf clinics are offered through Barrow Neurorehabilitation at St. Joseph’s Hospital. (Call Recreation Therapy Department at St. Joseph’s for more information @ 602-406-3606)

5. Additional clinics are offered through the Saving Strokes program facilitated by the American Heart Association and the American Stroke Association. (For more information on this national program, go to www.savingstrokes.com or call 602-414-5352 locally.)

6. Instructional clinics for all ages and abilities are available. We offer both on-hole play and 3-station clinics. Our first on-course youth adaptive clinic will be at Longbow Golf Club on April 16th. For more information, please contact golf@ability360.org.

7. Mentors: Jason Graber and Tim Surry are avid golfers and full-time wheelchair users. These two Ability360 staff members use adaptive golf as a vehicle for community integration and peer mentoring. You can find them at the Sports & Fitness Center to talk golf.
If you’re ready to take a swing, this is what you need to know.

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“The Globe Foundation and the Getz family have always made it a point to give back to the communities that we live in. Funding Ability360 and in particular, golfers with disabilities, we are excited to bring this wonderful golf cart to those in need. Chip’s volunteering at Ability360 and his passion for golf makes funding this need very rewarding.”

George Getz, The Globe Foundation

Donors:
When Ability360 decided to develop an adaptive golf program, it became clear we’d need to foster some great friendships and community partnerships. Founded in 1958, The Globe Foundation, a private family foundation based in Arizona, provided funding for the Stand Up and Play carts and the transportation requirements. This included a truck fit with hand controls, adaptive seats and a cargo trailer. Thanks to the Ability Center and Adapt Solutions, the truck was modified to include hand controls and seat lifts on both sides so that all of our qualified staff can say they’re “working” at the course. Longbow Golf Club generously donated our two Solo Riders.

Competition:
Once you’ve mastered the adaptive equipment, you can find opportunities to compete in existing golf tournaments, new adaptive golf competitions and unique events like the ParaLong Drive competition.

Golf is the one place where it’s acceptable to ask “what’s your handicap?” What’s yours?

Learn more at www.ability360sports.org
email golf@ability360.org

Corbin Beu plays competitive golf from a manual wheelchair.

Using the Stand Up and Play or Solo Rider is partial weight-bearing; make sure your bones are up to it. When’s the last time you were in a standing frame? If it’s been a while, you might get dizzy or risk passing out.

Arizona climate extends to the course; remember your hat and water, especially if your body does not regulate core temperature well.
Don’t forget your sunscreen!

Talk to your doctor about your limits.
Spunky, cheerful and tenacious, Isabella Mansfield is a newly-published poet, wife to Matt, and mother to "spit-fire" 5-year-old son, Travis. "The only obstacles I face are ones I put there myself," she says when asked about the struggles of her disability. Mansfield was paralyzed at age 12 from transverse myelitis, a virus that attacked her spinal cord. What brought on the virus is one of her life's greatest mysteries, but she firmly believes all things happen for a reason.

During her extended stay in the hospital 22 years ago, there were three mementoes from home that she kept close by: her teddy bear; the blanket made by her aunt; and the plaque from her dining room depicting Christ with the inscription, 'I never said it would be easy, I only said it would be worth it.' That turned out to be an apt encouragement in the face of things to come.

Pink Neck Tie
From At Arm's Length

You wrote a poem
For me

And gave it to
Me written
On the back of
A
Pink
Neck
Tie

I was flattered
Until I saw
The Noose
At the end
And how you
Strangled
My
Heart
With
It.
During her extended stay in the hospital 22 years ago, there were three mementoes from home that she kept close by: her teddy bear; the blanket made by her aunt; and the plaque from her dining room depicting Christ with the inscription, "I never said it would be easy, I only said it would be worth it." That turned out to be an apt encouragement in the face of things to come.

In fact, during her recovery process, she was sent to see several psychologists who were perplexed by her unconcerned mental state. As she would learn years later, one went so far as to describe her as "inappropriately cheerful." She recalls saying to them, "Look, I don't know what you want from me. I'll cry if you want me to, but let me ask you something... Will it change anything?"

That mindset is reflected in every facet of Isabella's life, including her writing. She found her creative voice with poetry at age 13, though her family would say she started writing the moment she learned to form letters. Poetry was her "sweet spot" she explains, "I can tell stories and people don't have to talk. I write really bad dialogue."

Isabella's poems explore the gamut of human emotions. The poems in her first book, At Arm's Length, published in 2014, were written over a sixteen-year span. "I was terrified of publishing, because these poems are so much like a diary or journal for me. The title, 'At Arm's Length' was chosen because I felt like, as a writer, I was finally allowing people to share in some of my most private thoughts - but selectively so, in that this certainly isn't ALL of my poetry. I was still keeping the reader 'at arm's length'."

She thought the book would just be a 'one-off', but the words kept coming. With the exception of one very short piece triggered by a visit to a friend's upstairs home, in her latest book, White Lies in Blue Ink, Isabella never writes about her disability. "I just never thought in terms of 'disability' before. I was the only one in my hometown who used a wheelchair, but I was still me."

Disability was still an afterthought in early online conversations with her future husband. Isabella met Matt in 1997, before online dating was a social norm. The pair continued to grow their relationship long distance, eventually marrying in 2005 and relocating to Phoenix in 2007.

After Matt completed his first year in film school, the couple decided it was time to start their family. Pregnancy turned out to be one of the biggest obstacles Isabella has ever faced. Travis was born eight weeks early and spent five weeks in NICU. After Travis' birth, Isabella experienced postpartum depression and started to dislike the person she saw in the mirror. Doctors put her on medication, but she didn't care for its effects and was concerned about her weight.

Looking for an alternative solution, she discovered the Ability360 Sports & Fitness Center and became a member. She worked out independently until someone suggested the weekly T.L.C. (Train, Lift, Condition) class and Bootcamp. That was three years ago, and she hasn't looked back.

"Weight management is difficult when you have a disability. I can't go run five miles when I want to, but I've lost thirty pounds, mostly since August thanks to the classes, and I feel better about myself. I've had to rethink some things since I joined Ability360 because it's the first time I've been around other people with similar struggles, but I like who I am now, at 35," Isabella explains.

Her fitness program has even helped her become a more energetic mom. "Raising a 5-year-old is exhausting," she freely admits, "but I know I've gotten stronger." Travis makes everything worthwhile. The little guy has never given much thought to his mom's differences in mobility until very recently. In fact, Isabella's wheelchair used to be his favorite walker, oftentimes leaving his mother momentarily stranded on the carpet. It's only in the last couple weeks that Travis has voiced any thoughts on the matter. "Mom, I wish you could walk," he said as he watched Isabella getting ready for the day.

"I don't," she replied. "If I did, I wouldn't have met your dad or have you. I don't walk, big deal. I can do lots of other things."

Isabella hopes that message is the take away from her books.

Both of Isabella's books are available online at Amazon and Barnes & Noble.
Building Futures with Local Families

Habitat offers an affordable mortgage loan for new home construction. Accessibility to meet anyone’s needs

Habitat partners with families who earn between 30 and 60 percent of the area median income:

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Habitat helps families who are:

- Currently living in substandard or overcrowded housing.
- Able to repay the affordable mortgage loan.
- US citizens or legal residents.
- Willing to attend homeowner education and financial fitness classes.
- Committed to sweat-equity hours, such as: 400 hours for new home construction or 200 hours for home renovation.

People of all abilities encouraged to apply

Phoenix (602)268-9022  Peoria (623)583-2417  habitatcaz.org
With just six months to go before Rio, the Arizona contingency is beginning to shape up.

Lisa Banta-Czechowski (Tucson, AZ) returns to six-member Team USA Women’s Goalball Team following the birth of her son (congratulations!). The team is still in contention for a qualifying slot.

Allyssa Seely (Phoenix, AZ) won the March Paratriathlon Championship in Sarasota, securing the first of three female spots. Back in Arizona, she is concentrating on training for her first Paralympics.

Eric Bennett (Surprise, AZ) already qualified for his third Paralympic Games, broke the Para Indoor World Record and won the Para Archery World Championship. He finished 7th in the able-bodied indoor National Championship.

US Track & Field Nationals in June will determine who makes the team USA squad. Nick Pryor (Phoenix, AZ), who works at the 360 Sports & Fitness Center, will compete in javelin throw and Erik Hightower (Glendale, AZ) in wheelchair racing.

There is no question that Team USA Wheelchair Rugby has a lot of pressure on them to win. Archrival Canada is ranked #1 in the world, and Team USA is not yet qualified for Rio. Team USA leaves for France in mid-April, determined to qualify for one of the last two spots.

Arizonans, Joe Delagrave (Chandler), Ernie Chun (Phoenix), Josh Wheeler (San Tan Valley), and Chad Cohn (Tucson) head to France for Rio team qualifications, then immediately head to Birmingham, AL, joining Joe Jackson (Mesa), Derrick Helton (Tucson) and Nick Springer (Phoenix) for Team USA tryout camp.
n the first week of June, the White Mountains will see its first campers arrive at the pine tree-filled campsite of Camp Tatiyee. The first campfire song will be sung, and new life-long friends will meet. Perhaps by then, a camper will already have planned a prank on the kitchen staff or learned a new skill. Some say that by the end of that first week, a camper’s life will be changed.

Since 1958, Arizona Lions Camp Tatiyee has impacted the lives of campers, campers’ families, and staff members with life-changing summers and one holistic mission: to enrich the lives of individuals with special needs by providing a life-improving experience to promote their emotional health, independence, self-esteem and confidence; all free-of-charge.

Camp Tatiyee, in Pinetop, Arizona, is divided into week-long sessions where campers with similar disabilities attend together. Campers who identify with physical disabilities, cognitive disabilities, multiple disabilities, and deaf or hard of hearing, each attend sessions geared to them specifically. Each week, campers enjoy activities like archery, science programs, go-cart racing, dancing and talent shows, all designed around the camp’s mission. The weeks are tailored for school-age sessions and adult sessions, but each promotes independence, self-esteem, health and confidence.

“It will change your life,” says Jace Brimhall, a former camper who has participated in Tatiyee for 16 consecutive summers. Brimhall, similar to many campers who attend, was born with spina bifida but has successfully grown to live independently. He now works as a camp counselor and says he looks forward to contributing in making new campers’ summer experiences just as fun and impactful as his were. “Knowing that makes me a little bit happier,” Brimhall says, “knowing that I helped them be happier.”

Brimhall laughingly recalls that The Parent Trap, a summer camp movie from 1999 starring Lindsey Lohan, led him to think that summer camp could be fun. Although Camp Walden in the 90s hit movie is a tough one to beat, Brimhall admits, “[Tatiyee] was a lot better than the movie!”

Nice try, Lindsey.
Brimhall credits Camp Tatiyee’s uplifting environment for his current lifestyle, saying his experience at camp helped him step out of his comfort zone. "I just have more confidence in myself," he says, "even though I have these physical differences... there’s nothing wrong with me." Since leaving small-town Snowflake, Arizona, the 26-year old has lived in Tempe and currently resides in Tucson.

Campers’ family members are also impacted by the non-profit, as they must learn to trust others to care for their loved one during an entire week. Susie Baker, the mother of nearly decade-long camper Eden, recalls dropping off her daughter at Tatiyee that first summer. "[Staff] were just really good at making me feel comfortable and secure, knowing she’d be taken care of," she says. Baker noted a natural hesitance to leave your loved one at camp but admits her daughter has benefitted greatly from the experience. "I think it’s just really hard to give up that control," Baker shared.

Baker also highlights Eden's increased confidence and newfound friendships after her first week at camp. Eden stays in touch with a lot of the Tatiyee friends from her nine summers.

Eden agreed, saying that her initial fears of being away from home were replaced with the inclusion she felt at camp. "People just get it," Eden says, "it's nice being in a place so accepting."

Eden and Jace both agree that the most memorable thing from their years as campers is simply the people.

Camp Tatiyee’s Director, Pam Swanson, who began as a camp counselor in 1984, admits she understands the concerns that both campers and their parents may have before a session. More so, Swanson says she keeps all of those concerns in mind throughout the hiring process. However, Swanson primarily looks for "people skills" during staff interviews, stating that camp staff should be people that genuinely want to be around and enjoy other people. "We are there for the campers," Swanson affirms, "to give [campers] an amazing experience... where people are trained to take care of all [of] their needs and want to be there."

Swanson says that staff, consisting of motivated college students alongside experienced returners, may be the most impacted participants at camp. "Staff are the forgotten token," she says, recalling the numerous stories of how impactful camp has been. With the staff slogan "campers first", it’s difficult to decide.

Some might even argue that the most impacted people are those who meet someone from camp but have never been to Tatiyee themselves, but maybe it’s not a competition. Among the pines and forest floor, the only real competition is deciding who can enjoy their time at camp more. Regardless, by the last week of July, hundreds of campers will leave the fresh outdoors with countless stories about their experience at Camp Tatiyee.
Road Trippin’ | Ability360 in the Wild
Why Mexico? Rocky Point is the closest ocean view from Phoenix—only a four-hour drive and just an hour over the border. Prices and weather tend to match Phoenix and Tucson. Spanish is helpful but not required, although a well-placed por favor or gracias can take you far.

Crossing the border requires a passport upon return. At the Mexican checkpoint stop, the Mexican border police may ask to look in your vehicle. Be friendly and cooperative and this process will go smoothly. Returning home, at the US checkpoint, you will declare your citizenship and present your passport. Upon entry or return, vehicles are randomly chosen for an enhanced inspection. Check in advance for the rules and restrictions on goods you can take over the border. You’ll also need auto insurance for Mexico. In many cases, your American policy writer will be able to assist you. We each paid about $25 for our four-day trip.

The Rocky Point Experience

ADA compliant ramps that would otherwise allow a manual chair user to push up and down solo were scarce in public areas of Rocky Point. A push up or guided descent were necessary to ensure safety. Even the most ardent among us was willing to sacrifice autonomy and accept an occasional push to get the very best views. While elevators were standard in the resort hotels, they were virtually non-existent throughout the city of Rocky Point.

Vendors and restaurant staff were eager to help, and offered to assist at every turn. It’s hard to say if this hospitality and eagerness applies to anyone who uses a chair, or if it was attributed to our tourist status.

Individuals with environmental disabilities need to be aware that nonsmoking areas are scarce and scented products abound.

When you arrive in town, find a place to whet your whistle and grab a bite. This might be a great time to shop. Once you settle in to your own beach view, “manana” sinks in fast. Time and ambition slow down and stillness prevails.

1 Las Palmas Resort on Sandy Beach with its exclusive beachfront homes 2 In Rocky Point, the shrimp is fresh daily. 3 Jennifer Longdon enjoys a siesta overlooking the Sea of Cortez. 4 The Point restaurant extends off the Malecon and is a great place for a seaside refreshment. 5 The Sonoran Sky Resort offers premier parking to its patrons with disabilities. 6 Videographer Clinton McDaniel chills at sunset at Los Conchas. 7 Shopping on the Malecon
Eat, Play, Shop

Our favorite meals:

Mariachis and Tequila (what can go wrong here?). If you can find it and you’re willing to brave a black diamond ski ramp, this Rodeo Drive restaurant is one the locals patronize.

La Curva has been part of Rocky Point forever. Access was easy. It is an expat favorite located in the suburbs.

The Point located on the pier at the Malecon offered a large wrap-around veranda over the water.

Street Food: Rocky Point is known for its plentiful "street tacos" and shrimp vendors. This is where your sense of adventure comes in. Not a street taco vendor per se, Lucas is one of our favorites.

Best sunset: El Capitan’s patio (get there early). The view is the best you’ll get, the drinks are cold, the food is...well, edible. Wheelchair access is a white-knuckle adventure – scary but worth it. Be advised that the trek to the best patio is not possible in a large power chair.

Rocky Point Geography

• **Downtown**, you’ll find shopping, ice cream, some hotels and the best restaurants. A festival can break out at any time.

• **Los Conchas**, to the east, where you’ll find the beach homes for rent; if you’re looking for ‘sleepy’, this is it.

• **Sandy Beach**, to the west, is the part of Rocky Point most people know best. Here you’ll find upwards of six resorts each with condos for rent. You can bring your own food and beverages and never roll the dice on local food and water. Each resort has its own restaurants, bars, pools, etc.

Sandy Beach Resorts:

Of all of resorts we visited, not one boasted a roll-in shower or hand-held shower head. A slight floor lip creates a barrier for some in the otherwise accessible showers. Make sure you do your homework, get good photos and ask for measurements if you have any doubts. These are each privately owned; hotel maintenance is not going to show up and remove a door or lower a mattress. Most of the accessible spaces available for rent have complete details available on-line.
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The Sonoran Sky:

- Luxury condos and breathtaking views
- Common grounds overall accessible, ramp to pools and tiki bar steep and winding
- Access to beach and palapas

Las Palomas:

- Largest resort in Rocky Point
- Numerous accommodations and staff amenities
- Exceptional access to restaurants, pool and lazy river (but no chair lift)

Las Palmas:

- Smallest and perhaps best-kept secret of Rocky Point accessibility
- Condos and 20 beachfront homes
- Single-level common grounds
- With enough ingenuity and adventure, you can get to the beach.

Watering Holes:

Many are on the second floor, with varying degrees of ramps and access, again challenging your sense of adventure.

- **JJ's Cantina**, the ultimate dive bar, is famous (or infamous);
- **Chongo's** has been there the longest;
- **Banditos** is owned by Arizona's home-grown rocker, Roger Clyne. When Roger and the Peacemakers are in town, get there EARLY.

Shopping:

- **Hit the Malecon**, the avenue of street sellers. Do feel free to haggle over prices; it's expected.
- **Rodeo Drive** is the place to work up your appetite shopping.

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360 Perspective

I couldn’t help but feel sad that two of my companions couldn’t go for a “roll” on the beach. Walking on the shifting sand admittedly increased my heart and breathing rate; the natural path would have required a Herculean effort by chair. Was the joy of the experience diminished for my comrades? I can’t answer that, but I do know that we were able to experience some of the most memorable moments in Mexico together: car karaoke; roadside shrimp stands; mariachi singers; bargain shopping, creative photo contests, insistent, early morning tamale vendors; mangoes on a stick smothered in lime juice, chile powder and salsa; lounging with drinks in hand; indescribable sunsets; whales breaking the surface ever so slightly; and enjoying meals together as the tide receded in our backyard.

Rocky Point is as accessible as your sense of adventure and your travel companions. Being outside of our routines, we wheelers were keenly aware that we were adding work for our able-bodied companions. Patience and a sense of humor were the order of the day.

Why Rocky Point? It’s a great launching pad for international travel as a person with a disability. And, there are no TSA hand searches. If one can manage the potholes and lack of ADA access, the world is your oyster. If you find it becomes more adventure than you’re up for, you’re only four hours from home.

1 Beach vendors offer everything from massages to mangoes right at your patio. 2 Ramps, where they do exist, do not always meet ADA standards.
3 360 team hard at work.
You’re invited to the 20th Anniversary of Day on the Lake

Thursday, May 19th through Saturday, May 21st
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TEACHING THE NEXT GENERATION OF HEALTH CARE PROVIDERS

by Gene Heppard

Students learn directly from a mentor what it means to have a health condition, how that changes over time and how the healthcare system impacts that person’s life.
am fairly confident that you or someone you know has had the moment of realization that a medical professional knows little or nothing about your disability or the knowledge to have a discussion regarding how you manage everyday life.

Maybe you find yourself navigating uncharted terrain as a newly-disabled individual (or that of a family member or close friend). Maybe you are a seasoned pro who is searching for a new medical professional due to elements out of your control. Maybe you are simply trying to take control of your health and well-being and want a medical professional who knows how to treat you – a person with a disability – with dignity and respect.

Seeking a relationship with a medical professional where your unique needs are met, your voice is heard, and that treating professional seems to know a thing or two about disability issues can be an exhaustive exercise in futility. I think the band Smash Mouth said it best in their song "Allstar," "Your brain gets smart but your head gets dumb."

Well, fear not fellow readers. The University of Arizona College of Medicine – Phoenix, Northern Arizona University and Arizona State University have teamed up to address this glaring oversight and disregard for basic human understanding. Together, these institutions of higher education are forging a new direction in patient and medical professional care by educating current students in the medical field in disability issues and etiquette. Please say hello to CHMP!

The Community Health Mentorship Program (CHMP), under the direction of Dr. Sarah Coles MD, is a collaboration between the University of Arizona College of Medicine – Phoenix, Northern Arizona University and Arizona State University.

This program matches a team of 3-4 interprofessional healthcare students, including physician assistant, occupational therapy, physical therapy, and nutrition and medical students with a Community Health Mentor. Mentors are members of the community with all types of disabilities.

The CHMP is designed to give healthcare students an opportunity to learn what really matters to individuals living with medical conditions. Students learn directly from a mentor what it means to have a health condition, how that changes over time and how the healthcare system impacts that person’s life. Students learn how home environment, family and relationships affect their mentor’s health and well-being. Students also learn how insurance, finances and mobility affect their mentor’s healthcare. The student team and mentor meet approximately every six weeks for one year for 1.5 – 2 hours for a total of eight visits. Each visit focuses on a...
Gene Heppard has been the Director of Disability Resources & Services and TRiO Programs at Phoenix College for the last 12 years. He previously worked at Arizona State University and Mesa Community College.

Gene completed a Master of Arts degree in Educational Leadership at Northern Arizona University, and firmly believes in the opportunities available for achieving a higher education degree.

Gene hails from a small Midwestern city in Illinois. He has called Arizona home for the past 22 years.

Community Health Mentor Program
http://phoenixmed.arizona.edu/students/curriculum/year-3-longitudinal-patient-care

Current topics in the CHMP include:

- Students begin their first visit by taking a Comprehensive Medical History of their Mentors.
- Students and Mentors discuss individual Barriers to Care and Community Needs and Resources.
- Students discuss Activities of Daily Living with their Mentors.
- Students conduct a Medication and Pharmaceutical Review with their Mentors.
- Students discuss a Nutrition Assessment with their Mentors.
- Students conduct a Home Needs Assessment with their Mentors.
- Students and their Mentors discuss Advanced Directives and Goals and Values in Healthcare.
- Students and Mentors discuss Advocacy and ways to improve the healthcare system and patient experience.

In the year I’ve been a CHMP mentor, I have forged a close relationship with the students. We meet every six weeks to discuss specific topics pertinent to their current class load and internships. Often, our discussion evolves into other areas of concern that the students have witnessed or noticed within their studies. I openly share my own experiences, both positive and negative, in order to prepare them for real-life scenarios.

Our discussions have been very open and informative on both sides of the issues. Asking follow-up questions and sharing individual experiences has opened my eyes to the difficulties students face in today’s medical arena. Hearing my story has hopefully given them insight into a world they view as a caring bystander. I think we’ve each learned more than we first expected.

The Community Health Mentor is the most important member of the team. The mentors’ participation and willingness to share their personal stories are vital to the learning experience of the students. Mentors also provide feedback about their experience with their students. This is a wonderful chance for mentors to develop meaningful relationships with students and play an essential role in training future healthcare professionals.
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DISABILITY LIBERATION WORKSHOP

April 20, 2016
9:00 AM - 3:00 PM
Ability360 Center

“The Liberation Workshop was a real awakening for me. I’m not alone.”

Ivan Rivera

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Moving Your Life Forward
www.AbilityCenter.com
Profiles of Living Well

by Kara Kahnke

Living Well with a Disability is a health promotion and wellness course designed specifically to help adults with physical disabilities live healthy, meaningful, independent lives. The course covers a wide range of topics such as goal setting, problem solving, coping with depression and practicing healthy eating. Participants develop goals during the 10-week course, and use class exercises and discussion to help them break down their goals into manageable pieces.

Steve Norton, past participant and current class mentor, said he is grateful for the extraordinary impact the class has had on his life. When he first learned about the class, Norton was still living in a care home. “After my stroke, I was staring at four walls wondering what I would do with the rest of my life, but I knew I had a lot of life left to live.”

During class, Steve set a goal of living on his own. By the end of the class, he accomplished this goal, just 11 months after his stroke. Norton continues to use the principles he learned in the class to accomplish major goals. He plans to open a café and cooking school within the year, which will allow him to benefit others through his training as a chef.

Sami McGinnis enjoys learning from people with different disabilities. As a result of her connections through the class, she is a mentor to Jolanta Chyla. Although their disabilities are not the same, McGinnis said that the two share a strong connection because both disabilities are progressive. They maintain a strong friendship despite living on opposite sides of the Valley. “There is so much to learn and so much to teach,” McGinnis said.

Doug Hocker particularly appreciated the resources he was exposed to in the class. He said learning to live with paraplegia has taught him that, “Having a disability means there is nothing constant but change.” Being in the class helped him meet others dealing with similar challenges. He learned about resources to adapt his car, which gave him a new sense of independence. “That’s the key to everything,” he said.

Angie Montgomery learned about the class when she came to Ability360 to learn how to avoid living in a care home after being diagnosed with an unknown form of multiple sclerosis. She described attending her first class in an uncomfortable hospital wheelchair. During class, she learned about a Wheelchair Skills class at the Ability360 Sports & Fitness Center, where she tried a more modern chair. “I didn’t know a real wheelchair could be so different. It was so much better,” she said.

Since completing the Living Well course, Montgomery has increased her independence by getting a power chair and is beginning the process of learning to drive. “This class changed my life,” she said.

Ability360 subsidizes the Living Well with a Disability course through donations and marquee sponsorship opportunities, which are currently available. Socialization Through Recreation and Youth Transition Coordinator Leanne Murrillo has been instructing the Living Well with a Disability course for the last three years. “I’m passionate about finding funding for this because I’ve seen how the students can grow and change through it,” she said.

www.ability360.org/LivingWell
LWD@ability360.org

Ability360 | Independent Living
Families Helping Families for Over 35 Years

by Maureen Mills, Communications Coordinator, Raising Special Kids

The year was 1979 and around one kitchen table in Phoenix sat a group of parents of children with disabilities. They may not have known it at the time, but these parents were about to change the landscape for parents of children with disabilities from birth through age 26 in Arizona. The determined group wanted to make sure new parents had somewhere to go, and most importantly, someone to talk to once they’d received their child’s diagnosis. Each knew first-hand the confusion and frustration of deciphering healthcare information, understanding their role in special education and how to manage the day-to-day experience of being a parent of a child with a disability.

Fast forward more than 35 years and that grass-roots organization has evolved into one of Arizona’s leading disability advocacy organizations -- Raising Special Kids. With offices in Phoenix, Flagstaff, Sierra Vista, Tucson, Tuba City and Yuma, the staff of 30 provides support to families throughout the entire state. The experienced and well-trained staff is comprised primarily of parents of children with disabilities, who are uniquely qualified to provide empathetic, high-quality guidance and information in a practical and useful way.

The heart of Raising Special Kids’ mission is parent-to-parent support. As a founding member of Parent to Parent USA, and with more than 300 trained parent leaders, new parents can be matched in one-to-one mentorships to gain the experience and knowledge of a veteran parent who’s “been there.”

Another important area of family support services is providing reliable healthcare information. Raising Special Kids helps families navigate systems of care by assisting them in understanding their health insurance benefits, and accessing community resources to meet their child’s unique needs. In cooperation with hospitals and medical centers, Raising Special Kids trains about 50 physicians in family practice and pediatrics each year. Physicians learn about improving communication with parents, especially when delivering a diagnosis, and how to be more sensitive to the needs of families of children with special needs. The

The Nico family of Buckeye, AZ, is one of thousands of families whose lives have been touched by Raising Special Kids.
two-part training experience includes a home visit as a way to introduce physicians to the realities of each family’s experience in caring for a child with a disability.

Families often need substantial assistance in the area of special education to ensure their child’s educational needs are met. Under Part D of the Individuals with Disabilities Education Act (IDEA), Raising Special Kids is designated as the Arizona Parent Training and Information Center (PTI). Families of children from birth to 22 receive training, information, and individual assistance in understanding their rights and responsibilities in special education.

In addition to fielding thousands of special education calls from parents each year, the staff provides workshops around the state on special education topics such as Individualized Education Program (IEP) training, Positive Behavior Support (PBS) and Turning 18, which covers the legal options and considerations for families when a child with a disability reaches the age of majority.

The highest level of special education support Raising Special Kids provides is one-to-one IEP support where PTI staff attend an IEP meeting with a family; a service that is not available for every situation. Parents who have a disability, grandparents who are raising grandchildren with special needs, or recurring special education issues in a single school district are often reasons for an IEP Partner to assist the family and the school with appropriate and effective advocacy to improve educational results for children with disabilities.

In almost every state, parents can find support and assistance in various programs and services for children with disabilities. In Arizona, many parents find comprehensive assistance and advocacy information available at no cost, and under one roof, at Raising Special Kids.

Raising Special Kids

Ability360 Center
5025 E. Washington St.
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Phoenix, AZ 85034

602-242-4366 or 800-237-3007; info@raisingspecialkids.org; www.raisingspecialkids.org
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Women’s Empowerment
Through Sacred Play

Invincible Courage! Auspicious Beauty! Destroyer of Negativity! Serene Peace...

All divine feminine qualities attributed to the enlightened Bodhisattva, Tara, explored in the Ability360 Women’s Empowerment Group which meets at the Ability360 Center each month.

While Ability360 and other community groups provide women’s support groups, this group is something different. “This group is for the woman who enjoys singing and gentle movement with other women while celebrating our divine and powerful selves,” says facilitator Amina Kruck.

The monthly class is based on a practice from an ancient Tibetan Buddhist tradition, but one does not need to practice Buddhism to participate. Kruck explains that the components are transferable to support a variety of abilities and spiritual paths. It’s not for everyone. Those that embrace the class have a blast. “All abilities are welcome!” Kruck enthusiastically explains. “This practice is an opportunity to attune to and honor ourselves as women through the revealing and unfolding of Tara’s 21 qualities. Think of this as self-esteem aerobics.”

Kruck’s facilitation of Disability Liberation/Attitudinal Barriers classes has helped many people with disabilities change their self-concepts over the years. She explains: “I grew up with a physical difference; I have been fascinated with how people often internalize negative disability stereotypes and mistakenly think that is who they are... broken, invisible, incapable, a burden, unattractive, lazy, melodramatic, and so on. We are much more than our medical condition or society’s...
ableist stereotypes." When she began practicing this particular discipline, Kruck recalls thinking, "This is the best contradiction to disability oppression and ableist attitudes I have ever seen!"

Some women wonder if they will be able to participate at their own level of ability. Kruck is quick to reassure and encourage: "Since we all have a variety of disabilities, everyone gets to decide how to adapt it to their own abilities and spiritual paths. What we share is our experience with this empowering practice done together. There are lots of parts that take time to learn, but any part that sticks is empowering."

Aricia Davison has participated in Women's Empowerment since it began four years ago. She describes the class as "centering", explaining that the class helps her to focus on what's important.

"We dance," she exclaims. "That's the point. We can all do it. Women come in wheelchairs that do it." Davison self-describes that she does not hear well and has trouble with motion due to a torn muscle in her hip. After dancing, she has experienced improved balance and flexibility. "I'm a regular," she proudly announces. "We all have challenges, but we all can do it."

Register at least three days before the group meets and include any reasonable accommodations to participate.

Ability360 also has a 7-week women's self-esteem group. Contact aprir@ability360.org or call 602-296-0533 for details and accommodations.

Ability360 is a fragrance-free environment. Please do not wear any perfume or scented personal products to this group or any other event at Ability360. ☺

"Think of this as self-esteem aerobics."

Ladies
Try Something Different
Join us for Sacred Play at
Women’s Empowerment Group
First Saturday of each month
1:00 pm - 3:00 pm
Classroom A / Ability360 Center
Facilitator: Amina Donna Kruck
RSVP: 602-443-0722 or aminak@ability360.org and please use the subject line: "Women's Empowerment Group"
DISABILITY LIBERATION WORKSHOP - April 20
9AM - 3PM | Ability360 Conf. Center
Eliminating Attitudinal Barriers
Register: www.ability360.eventbrite.com
Emily Lopex (602) 443-0738

MEN’S DISABILITY GROUP
Thursday, April 21
5:30PM - 7PM (Every 3rd THURS)
Ability360 Classroom B
Adult men only!
Don Price (602) 980-3232

VALLEY METRO/FREE LIGHT RAIL RIDE
Wednesday, April 20
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Ability360 Classroom A
Phoenix transit system overview.
David Carey (602) 443-0723
davidec@ability360.org

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Friday, April 29: 12PM - 5PM
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FREE to the public! Contact David Carey
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Educational Presentations
Exhibition Booths
Resources - Networking - Support

Wheelchair Lacrosse
April 16, 8:30am – 3pm
Sports & Fitness Center Mixed team sport for male and female wheelchair athletes.
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