



Missouri Developmental Disabilities Council

Spring Newsletter, 2017

Executive Director, Vicky Davidson



IT'S HAPPENING

Adults with intellectual/developmental disabilities (I/DD) are being verbally, fiscally, physically, and sexually abused.

The abuse is prevalent and pervasive, it happens in many ways, and it happens repeatedly to victims with all types of disabilities.

and we can stop it.

1

IT'S HAPPENING

Most people in our society refuse to believe that anyone would even consider abusing, neglecting or exploiting a person with an intellectual or developmental disability (I/DD). But it's happening every day.

2

SUSPECT SOMETHING?

You don't have to investigate. If you suspect something, report it and the professionals will take it from there. You'll stay as anonymous as you want to be.

3

REPORT IT

Reporting is anonymous, easy, and final. Only be as involved as you choose to be.

Call the Adult Abuse, Neglect and Exploitation Hotline at:

(800) 392-0210

7 a.m. - 12 a.m., 365 days per year
(choose "anonymous" option if desired)

Get more information or report online:

andwecanstopit.org



The Missouri Developmental Disabilities Council is a federally funded, 23-member, consumer-driven Council appointed by the Governor. Its Council mandate is to plan, advocate for, and give advice concerning programs and services for persons with developmental disabilities that will increase their opportunities for independence, productivity, and integration into communities.

The "It's Happening" I/DD Victimization Awareness campaign was funded through a grant from the Missouri Developmental Disabilities Council under provisions of P.L. 106-402, the Developmental Disabilities Assistance Bill of Rights Act 2000.

The "It's Happening" I/DD Victimization Awareness campaign was sponsored in part by the Arc of Missouri.



Like us on Facebook
[/andwecanstopit](https://www.facebook.com/andwecanstopit)



Follow us on Twitter
[/andwecanstopit](https://twitter.com/andwecanstopit)

The MODDC established a Victimization Task Force to address the victimization of people with developmental disabilities. We awarded a grant to the Arc of the US—Missouri Chapter, to develop an awareness campaign as one of many ways, to address this serious issue. You can learn more about Missouri’s effort by visiting the website: www.andwecanstopit.org. Everyone can play an important part in stopping the victimization of individuals with developmental disabilities. Executive Director, MODDC, Vicky Davidson

THE SIGNS

.....While it’s vitally important to know and see the signs, it’s also critical to ask the individual you suspect may be experiencing abuse about their situation. Most people with I/DD that have experienced abuse state that they were never asked about being abused, neglected or exploited. If the suspected victim discloses abuse, neglect or exploitation, please [report it](#) even if the details are inconsistent.

KNOW & SEE THE SIGNS

Physical signs of abuse may include:

Questionable bruises, scrapes, cuts, welts, and burns; bite marks; imprint injuries (marks shaped like fingers, thumbs, hands); sudden/unexplained hearing loss; broken/missing teeth; spotty balding (from pulled hair); eye injuries (black eyes or detached retinas); vaginal or rectal pain, trauma to genital area, frequent urinary tract or yeast infections, painful urination, incontinence (in someone who was previously toilet-trained); sudden onset of psychosomatic complaints (persistent stomach aches and headaches); sudden difficulty walking or sitting; repeated dislocated joints, multiple fractures; or unexplained coma (often resulting from shaking).(2)

Physical signs of neglect may include:

Poor grooming and/or hygiene, presence of lice, smell of urine or feces on the person, dirty or soiled clothing; weight loss; poor skin condition (rashes, open wounds, bedsores); dehydration; lack of necessary adaptive aids (glasses, hearing aids, braces, walkers); improper medication management; lack of medical/dental care; or lack of supervision.(2)

Behavioral signs of abuse may include:

Aggressive behavior including yelling, hitting; acting out what was done to victim by replicating the assaultive act upon others; violent drawings/stories; fearfulness of abuser, of others in general (may be age or gender specific), or of specific places; sudden fear of bathing or toileting; sudden noncompliance; sudden detachment/withdrawal; sudden unacceptability with physical contact; regression from skills already mastered; sudden interest in sexual matters, onset of increased sexual conduct, inappropriate displays of affection; self-harm; self-molestation (replicating assaultive act upon oneself); onset of new fears; sudden social anxiety or phobia; persistent anger; change in appetite, change in energy level, change in interest in normal activities, irritability/mood swings, depression; changes in sleep patterns, onset of nightmares; onset of lying; cruelty to animals; selective mutism (previously verbal individual stops talking); or any unexplained and unusual change in behavior.(1,2)

Financial Exploitation of those with I/DD

Financial exploitation of those with I/DD directly affects the victim’s ability to lead an independent life by limiting their ability to afford the basic necessities of life, such as food, rent payments and medicine.(1)

If you suspect financial exploitation, please [report it](#).

Financial exploitation signs may include:

Sudden decrease in bank account balances; sudden changes in banking practices (large withdrawals); sudden problems paying bills, buying food or other necessities; sudden changes in wills or other financial documents; unexplained disappearance of money or valuable possessions.(1)

1 From the website of the Agency for Persons with Disabilities, Tallahassee, FL

2 Baladerian, N.J. (1997). Recognizing abuse and neglect in people with severe cognitive and/or communication impairments. *Journal of Elder Abuse and Neglect*, 9(2), 93-105.

New Project Announcement:

The Arc's National Center on Criminal Justice and Disabilities® (NCCJD) and The Board Resource Center (BRC)

Posted on January 26, 2017 by The Arc

Building Capacity of Primary Care Providers to Discuss Sexual Violence with Women with Intellectual/Developmental Disabilities

Introduction

In September of this year, The Arc's National Center on Criminal Justice and Disability® (NCCJD) was awarded a one-year grant from The Special Hope Foundation. Working with The Board Resource Center, a California-based consulting firm, this funding will be used to teach health care professionals about how to address and help prevent sexual violence against women with intellectual/developmental disabilities (I/DD).

Background

This project will address the alarmingly high rate of sexual violence experienced by women with I/DD. About 20% of all women are sexually abused each year. However, women and girls with developmental disabilities are four to ten times more likely to face sexual abuse. Up to 68% of women with developmental disabilities will be abused before they are 18, and up to 90% will experience abuse during their lives (Valenti-Hein, D. & Schwartz, L. 1995).

Health care providers are in a unique position to have open dialogue about sexual violence prevention with their female patients. However, many times they do not have experience talking about victimization with women with I/DD in a manner that is accessible and culturally competent for all. In order for providers to have meaningful conversations about the high risk of violence people with I/DD

face, they need training on effective ways to provide patients with safe environments to share their experiences, often for the first time.

By learning how to use effective plain language communication strategies, they can provide a safe place for women to share openly. These strategies can improve communication with all patients, since plain language strategies apply to a number of different populations who struggle with comprehension of information. Ultimately, this project will improve health care delivery by giving providers effective tools to support women with I/DD to discuss or disclose sexual violence.

Project Objectives

This project, funded by The Special Hope Foundation, builds the capacity of primary care providers to discuss the high risk of sexual violence women with I/DD face. It will equip providers with training and tools to create safe, open, and accessible

conversations about what sexual violence is and what women can do to report it or stop it from happening. Together, and under the guidance of an advisory committee, we will achieve the following objectives to decrease the incidence of sexual violence: 1) Develop two training videos and materials on discussing sexual violence with female patients. 2) Disseminate tools to health care organizations, regional centers, advocacy groups, and people with I/DD and their families, ultimately reaching 500,000 individuals.

Both The Arc and The Board Resource Center have a shared vision that emphasizes accessibility, education, and empowerment for people with I/DD.

References

Valenti-Hein, D. & Schwartz, L. (1995). The sexual abuse interview for those with developmental disabilities. James Stanfield Company. Santa Barbara: California.



DISABILITY AND TOKENISM: WHY NO ONE CAN SPEAK ON BEHALF OF EVERYONE



By Burgandi Rakoska
Wednesday, December 21, 2016

Article courtesy of Rooted in Rights :www.rootedinrights.org

Why is it that so many people look at a single person from a minority group and automatically assume that they represent the group as a whole? Nowhere does this issue, known as **tokenism**, seem more prevalent than in higher education. In my experience, it's been a huge problem.

As an Early Childhood Education Major, I often study the different ways to incorporate inclusivity in our classrooms. Each semester, I have to try not to flinch as my classmates get whiplash from how fast they turn to look at me when the word "disability" is mentioned.

Keep in mind, I have spent years working with students with disabilities, reading dozens upon dozens of scholarly articles on different teaching methods and approaches, and joining advocacy efforts of multiple organizations. But in the eyes of my classmates, these credentials aren't what qualify me to speak on behalf of students with disabilities. No – my wheelchair is what qualifies me.

Apparently, having a disability means I have the authority to answer every single question that has to do with disabilities. In addition to assumptions made by my classmates, I have faced an endless line of professors calling on me time and time again when it comes to the topic of disabilities. Make no mistake – I am happy to share my opinions, including those based on the research and professional knowledge that I have gathered. However, it is unfair for professors, faculty, and administration to assume that my disability means I'm able to speak on behalf of every single person who has a disability.

Each person with a disability has different needs, different opinions, different personalities. Each student with a disability requires different accommodations based on their individual strengths and weaknesses. So, I cannot tell you what a blind student needs to succeed any more than they can tell you what I, a wheelchair user, needs to succeed. Nor can I tell you what another student in a wheelchair needs to succeed anymore than they can tell you what I need.

I think I speak on behalf of everyone when I say that it is impossible to speak on behalf of everyone.

We all want to feel like we have the power to be a voice for others. But the truth is that we all only have one voice. It is not fair for nondisabled students and college professors to look onto a disabled student with the expectation that they can be the token voice for an entire community, and it is not fair for a disabled student to speak for everyone. Even if they are called upon to do so, it is important to remember that differing views *must* be brought to the table if a classroom is to ever truly be inclusive. For inclusivity does not mean simply listening to one voice. Inclusivity is about hearing as many voices as possible, exposing yourself to as many opinions as possible, and seeing the reasoning behind each and every stance surrounding an issue.

Burgandi Rakoska is a fifth-year Education Major at the State University of New York at Fredonia. Born with Spina Bifida Occulta, Burgandi began using a wheelchair at the age of twelve and has spent the past ten years advocating for herself and other people within the disabled community. This advocacy has led to her involvement and connection with multiple organizations including the SUNY Student Assembly, the SUNY Fredonia Students with Disabilities Union (of which she was the co-founder/president), the New York State Disability Services Council, 3E Love, the American Association of People with Disabilities, Handicap International, and now, Rooted in Rights.



HB 626 & SB 465 Revisions to Missouri Guardianship Law, Chapter 475, RSMO

Why Change the Current Law?

- Current law was enacted in 1983; things have changed.
- Various alternatives to guardianship and conservatorship that aren't recognized by the law (i.e. Durable Power of Attorney, Health Care Directives, Special Needs Trusts, Estate Planning Devices, Division of Assets Provisions, Supported Decision-Making etc.).
- Overuse of Public Administrators.
- Little guidance for guardians.
- Little "person-centered" planning required; greater emphasis on managing property and money and little focus on the person themselves.

What Will the New Legislation do?

- Follows recommendations of the Missouri Working Interdisciplinary Network of Guardianship Stakeholders (MO-WINGS) and national standard-setting groups.
- Emphasizes least restrictive alternatives.
- Clarifies when and whom appointments are made for guardians and conservators.
- Combines person-centered standards of "best interest" and "substituted judgment" for guardians to make decisions.
- Adds rights for the ward/protectee (person overseen by guardian or conservator).
- Sets new person-centered standards for conservator decisions.
- Establishes methods for terminating guardianship or conservatorship and restoring full or partial rights to the ward/protectee.
- Facilitates processes for setting new policies and training judges, lawyers, Public Administrators, guardians, conservators, and consumers on best practices under the new provisions.



*"to assist individuals, families, and the community to include all people with developmental disabilities in every aspect of life.
An Equal Opportunity Employer; services provided on a nondiscriminatory basis.*

Grassroots Advocacy with Katheryne Staeger-Wilson



Spring into Action

The 2017 Statewide Self-Advocacy Conference

Breakout Sessions Include:

- Anyone Can Lead - That Means You!
- Who's in Charge? Self-Directed Supports
- Map Your Money Using the LifeCourse Star
- Meet the New Project STIR
- How to Run Great Meetings
- Charting the LifeCourse: Getting Your Good Life
- Defend Yourself! Parts I and II
- Spread the Movement: Building Chapters
- On Our Own: Self-Advocates Living Independently
- Reaching Youth Today: The Next Wave
- Victimization: The Signs and What to Do
- ...and more!

Conference Registration

\$95 Per Person - includes three meals, participation in all events, & conference materials. Hotel not included.
T-shirts - \$5 each

Hotel Reservations

Must be made separately through Tan-Tar-A Resort by calling (800) 826-8272 or at Tan-Tar-A.com. Room rate is \$95+tax per night of stay for up to four people.

Keynote Speaker

Julie Petty

National leader in the self-advocacy movement, founder of People First of Arkansas, and former president of Self-Advocates Becoming Empowered (SABE)



Featured Speaker

Chuck Graham

Associate director of the Great Plains ADA Center at University of Missouri-Columbia, served four years as a Missouri state Senator and eight years in the state House of Representatives



Endnote Speaker

Chris Worth

Activist, Community Organizer, Self-advocate and Team Manager at Paraquad; former lead organizer for the Enable Project Appalachia and volunteer organizer in the environmental movement for over 12 years



People First of Missouri

April 21-23, 2017 Tan-Tara-A Resort
Osage Beach, MO

Use this link to register: <https://www.missouripeoplefirst.org/>

REGISTRATION:

Deadline - April 15, 2017

Full Registration - \$95

Includes all sessions, materials, two meals on Saturday, and Sunday brunch

Saturday Only - \$75

Includes Saturday sessions, materials, and two meals

Sunday Only - \$50

Includes Sunday sessions, materials, and brunch

Late Registration - After April 15

Same registration options and fees as above but meals are not guaranteed to be included

HOTEL INFORMATION

Each registrant is responsible for reserving and paying for their hotel room. Make your reservation by contacting:

Tan-Tar-Resort:

(800)826-8272 or (573)348-3131
Room Rates - \$95 / night
Single/Double (1 - 4 adults)

A block of rooms is reserved under code "PEOP." A limited number of accessible rooms are available on a first come, first served basis. Make your reservations as soon as possible for the best room choice.

Please REGISTER ONLINE at: MissouriPeopleFirst.org

If you are unable to register online, you may use the form below.

Conference Agenda

Friday, April 21, 2017

- 5:00 pm Registration
- 7:00 pm Welcome Reception
- 7:30 pm Networking
- 8:00 pm Dance and Karaoke

Saturday, April 22, 2017

- 9:00 am Registration
- 9:30 am Welcome and Flag Ceremony
- 10:00 am Keynote Speaker - Julie Petty followed by the Heartland Self-Advocacy Resource Network panel
- 12:00 pm Lunch on your own
- 1:15 pm Featured Speaker - Chuck Graham
- 2:15 pm Breakout Session 1
- 3:30 pm Break
- 3:45 pm Breakout Session 2
- 5:00 pm Break
- 6:30 pm Dinner and Award Ceremony
- 8:15 pm Dance

Sunday, April 23, 2017

- 9:00 am Breakout Session 3
- 10:30 am Brunch and Endnote Speaker - Christopher Worth
- 12:30 pm Closing Ceremony and Door Prizes

Breakout Session Topics

Session 1:

- A. Charting the LifeCourse
- B. PFMO Chapters in Action, Past and Present
- C. Victimization: The Signs and What to Do
- D. Anyone Can Lead... That Means YOU!
- E. Who's in Charge? Self-Directed Supports

Session 2:

- F. Defend Yourself, Part I
- G. How to Run Great Meetings
- H. Map Your Money Using the LifeCourse Star
- I. Meet the New Project STIR
- J. Disability Rights - Take Action

Session 3:

- K. LifeCourse Tools for Advocacy
- L. Spread the Movement: Building People First Chapters
- M. On Our Own: Self-Advocates Living Independently
- N. Defend Yourself: Part II
- O. Reaching Youth Today: The Next Wave

ALTERNATIVE REGISTRATION FORM DIRECTIONS:

- 1) Cut on the line below.
- 2) Mail one form for each participant with your check or money order.
- 3) Write name(s) of attendees on payment.

4) Mail to: People First of Missouri
UMKC-IHD
215 W. Pershing Rd., 5th Floor
Kansas City, MO 64108

2017 People First of Missouri
Spring into Action Statewide Self-Advocacy Conference

Please Check Registration Type:

Full Registration: \$95 _____
Saturday Only: \$75 _____
Sunday Only: \$50 _____

Remember to allow for mailing time. Registrations must be received by cutoff date of April 15 for guaranteed meals.

Name _____

Address _____ Phone _____

City _____ State _____ Zip _____ Email _____

_____ I would like to purchase a conference T-shirt - Add \$5 to check or money order

Size (circle one): Small Medium Large X-Large XX-Large XXX-Large

Which breakout sessions will you most likely attend? (Circle one for each session. Topics are listed above, right section.)

Session 1: A B C D E Session 2: F G H I J Session 3: K L M N O

Accommodations needed (e.g., ASL Interpreter, Large Print or electronic communications, diet restrictions, etc.) _____

Employment and Transportation with Chaz Nickolaus



Systematic Instruction



EMPLOYMENT FIRST
EMPLOYMENT NOW

Systematic Instruction is an approach intended for those working directly with people who require additional support to learn the practical skills involved in work and independent living. Originally, it was conceived with those with learning disabilities in mind, but its relevance and effectiveness to reach across many groups has become obvious, including to people with autism, Asperger's syndrome, users of mental health services and basically anyone who lacks confidence and/or needs support to successfully undertake and learn the practical tasks involved in work.

Systematic Instruction (SI) fits broadly into the in-work support element of the 'Supported Employment' approach. It was originally devised by Dr. Marc Gold, an American Psychologist who conducted his pioneering research in the mid 1970's and early 80's.

The model task used in SI was and often still is the bicycle brake – not an ordinary caliper brake, but a complicated hub brake. The bike brake, used as a 'model task' has some very positive properties which make it excellent for SI purposes - it can fit on a desk, provides a complicated challenge to the course participants; and maybe most importantly, it has a focus on 'practical' rather than 'academic' skills. This allows us, as SI advocates, to demonstrate, that whereas, many service users do not fare well on academic tests, (hardly surprising if they have a learning disability) but can and do perform very well on practical ones.

Marc Gold once said that he could find no correlation in his data between people's IQs and their ability to perform practical tasks. Many researchers concur with this: and found absolutely no correlation between peoples' academic abilities (course participants and the helpers with disabilities) and their ability to do practical tasks indeed.

Missouri APSE (www.apsemo.org) is very happy to announce three opportunities to learn more about Systematic Instruction from one of the leaders in the field, Teri Johnson. Each session will provide an overview of the components of Systematic Instruction. They will also provide research based strategies for analyzing and conducting task analyses and systematic teaching of workplace tasks.

The opportunities are:

- March 29, 2017- Kansas City
- March 30, 2017 - Jefferson City
- March 31, 2017- St. Louis



Disability, Abuse, Schools, and Risk Management

So you think children with disabilities are safe at school: think again.

By Thomas F. Coleman

We at the Disability and Abuse Project have been collecting news articles about abuse for several years. We have a weekly newsfeed that gathers together the good news and the bad news related to abuse of people with disabilities. Unfortunately, there's more bad news than good.

Each week we send out a list of more than 100 such articles from throughout the nation and some international stories as well. We can't read them all, but by gathering, listing, and sharing them with others who have an interest in this topic, we keep our hand of the pulse of what is happening. It's alarming to us and should be to everyone.

Our information does not just come from news stories. We read professional journals as well. We also attend conferences. We even conducted our own national survey on disability and abuse, gathering information from more than 7,200 people – many of them people with disabilities and their family members.

Dr. Nora J. Baladerian, our project director, has been working in the field of disability and abuse for decades. She does trainings on the topic for law enforcement and protective services agencies. She treats trauma and abuse victims. She is hired by plaintiffs' attorneys to evaluate abuse victims and their families to assess damages. In other words, her involvement in this field is multi-dimensional.

I have worked by Dr. Baladerian's side for several years as a legal consultant, soaking up all of the information I can find on issues such as prevalence, risk reduction, and response. I have also done my own independent review of academic literature on the topic. Everything points in the same direction. Abuse of children with disabilities is too prevalent. People with disabilities are at a higher risk of abuse

than people in the generic population. Studies indicate that a majority of people with disabilities may have been victims of abuse of one sort or another during their childhood years. This includes physical, sexual, and emotional abuse. Most perpetrators are not strangers but rather someone who has ongoing access to the child.

What she has learned as a forensic expert is that children with disabilities, especially those with cognitive and communication disabilities, are not necessarily safe at school. Most of her consulting work involves lawsuits against schools.

The newsfeed we have been publishing for the last several years confirms that too many children with disabilities are being abused at school – by teachers, teacher aides, bus drivers, and other students who lack proper supervision. Searching our database of published news stories about abuse during a 12-month

period in 2015 and 2016, I found some 240 articles about victims with disabilities abused at school.

This is the tip of the proverbial iceberg. Most incidents of abuse are never reported to authorities, much less finding their way into a newspaper. Being vulnerable and often nonverbal, many victims are not able to complain at school or tell their parents at home. When abuse is witnessed by a member of the school staff, the immediate reaction may be denial. Coverups are not uncommon.

Parents may see signs and symptoms of abuse, but they don't connect the dots. They naively believe the school system is a safe place. They cannot imagine school personnel abusing their child. They have never been told about the rate of abuse of children with disabilities. So they often seek alternative answers to explain these symptoms.



Then, after a witness comes forward or the police are notified, parents are informed. All of a sudden they realize they were discounting warning signs that were there for weeks or even months. They feel guilty because had they realized the source of the problem sooner, they could have saved their child from further harm.

Dr. Baladerian's evaluations are used by plaintiffs' lawyers to demonstrate the extent of damages suffered by the victim directly and by the family members vicariously. When the lawyers defending the school see the evaluation, they usually settle the case rather than going to trial.

Liability is usually not an issue. It is clear that the abuse was intentional and the district was negligent in allowing it to happen or continue. There is often not a clear policy on abuse, or training on the duty to report, or a risk reduction program. Risk reduction and reporting of abuse of children with disabilities have not been school priorities.

Settlements are often not publicized, so the negligence of many school administrators remains under the radar. But sometimes a settlement receives considerable publicity.

Take, for example, abuse that occurred at the Antioch School District in California. The district agreed to pay an \$8 million settlement in 2013 for abuse of several students by a special education teacher there. Perhaps such financial liability – and harm to the students and their families – would have been avoided if the district had properly trained staff on the subjects of risk reduction and response.

Why such a large payout? Research shows that damages to child abuse victims are not limited to the events themselves or to the immediate future. Trauma can have lasting effects. A major study by Kaiser Permanente (Adverse Childhood Experience Study or ACES) showed that adverse medical and psychological consequences can last well into adulthood, or emerge after years or even decades of simmering below the surface.

If not for the sake of their students, school districts should find it in their financial self interest to take pro-active measures. They should be aware that any school setting which has students with disabilities is a high-risk environment. They should take appropriate measures to reduce the risk of abuse.

Parents of special education children should be informed about statistics on the prevalence of abuse and be given tips on the signs and symptoms that it may be occurring. Districts should adopt a zero-tolerance policy on abuse, warning personnel that they will be fired if they commit abuse or if they observe it and fail to make an *immediate* report.

Each school should have a risk reduction program and should train personnel on how to minimize the prospect of it occurring. Education and training of teachers, teacher aides, school nurses, counselors, clerical staff, and even janitors, is essential.

Risk reduction of abuse should be on the agenda at school administrator conferences. Insurers should make risk reduction and response planning a condition of insurance coverage.

Abuse of children with disabilities at school should become a political issue. Disability organizations should bring the matter to the attention of local school boards and state legislators.

Discussions about the inconvenient truth of disability, abuse, schools, and risk management are long overdue. Remember: *Silence = Abuse*.

www.disabilityandabuse.org/risk-management.pdf

Thomas F. Coleman is the legal director of the Disability and Abuse Project of Spectrum Institute. Resources and reference materials on this topic are available at: www.disabilityandabuse.org. He may be reached at tomcoleman@disabilityandabuse.org

Dr. Nora J. Baladerian is a clinical psychologist specializing in abuse of people with disabilities. She may be reached at nora@disability-abuse.com

Disability and abuse risk reduction should be on the agenda at conferences of school administrators. Insurers should make risk reduction and response planning a condition of coverage.



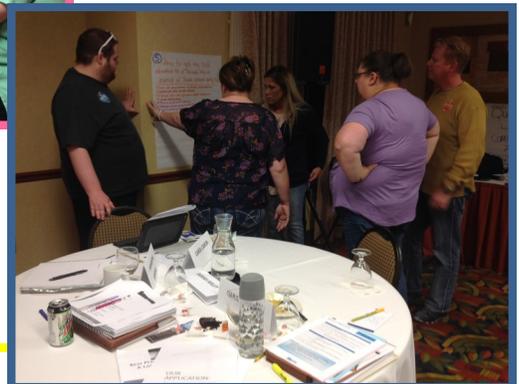
@nodisabledabuse

Partners in Policymaking....

Inclusive Education Weekend with Patrick Schwarz



This year's participants are: Allen Nelson, Carol Caron, Carolyn O'Laughlin, Colette Canchola, Daniel Taggart, Debra Mixon, Edie Kennard, Jeff MacGowan, Jeremy Turner, Jordana Vera-Montero, Juliet Salih, Kayla Aldridge, Kayla White, Mirinda Decker, Misty Long, Rachel Baskerville, Samantha Solberg, Sarah Miley, Sarah Rotert, and Scott (Tim) Steelman-Rhoden.



*Our Council Member Cathy Enfield will be awarded
the 2017 Mental Health Champion!*



AWARD ANNOUNCEMENT 2017 Mental Health Champion

(Independence) – Cathy serves as the President of the Missouri People’s First, National Vice President of Self Advocates Becoming Empowered (SABE), past Chair of Missouri Protection and Advocacy, and board member of The Arc Missouri and the Missouri Developmental Disabilities Council. She is a graduate of Partners in Policymaking. She is also the recipient of many honors including the Roland Johnson Self-Advocacy Award, Bernece Hobson Meritorious Service Award (Eitas – Jackson County MO SB 40 Board), and the People First of Missouri Self-Advocate of the Year. In working with her State Representative, legislation passed changing language on parking signs from “handicapped” and “disabled” to read “accessible”. Cathy has pursued her lifelong goals of helping people with disabilities and speaking out for those that cannot speak for themselves. She has made those goals a reality against great odds.

We love hearing about what our Partners in Policymaking Graduates are doing in their communities. This story comes from **Tim Brooks of St. Louis. Thank you**

for sharing with us Tim!



On January 27, Concord Elementary School in St. Louis had an Abilities Awareness Day. Abilities Awareness day at Concord started in 2008. The overall goal of the day was to offer each student the chance to experience an ‘AHA’ learning moment about how to embrace each person’s talents and abilities. We also hoped to provide an open and honest forum for the students to ask questions. This year’s event started with an all school assembly with a fifth grader, Jordan Reeves of Columbia, and her mom Jen. Jordan was born with short left arm. She and her Mom presented about differences and how to talk about them.

After the assembly, the third and fourth grades each broke out into four mini sessions about people with disabilities. Speakers included former and current students talking about Down Syndrome and people first language. The Easter Seals came and spoke about living with autism. The Delta Gamma Center made a presentation on children with visual impairments. Jen and Jordan Reeves spoke about the different technology available with 3D printers to help people with disabilities. Ryan Brooks, a current third grader at Concord, gave a presentation to the fourth graders about living with Cerebral Palsy.

Overall, the day provided students with opportunities to learn more about disabilities and to not be afraid to ask questions. Jen Reeves said, “It was so heartwarming to see an entire school pay close attention to Jordan's story of life with one hand. It was an honor to be a part of a school that celebrates and teaches about all types of abilities.”

ReWalk™
More Than Walking.



The Department of Veterans Affairs has agreed to pay for robotic legs that could allow scores of paralyzed veterans with spinal cord injuries to walk again.

Veterans have been petitioning the VA to do this because many cannot afford the \$77,000 needed to pay for the powered exoskeleton called the ReWalk. The device was approved by the U.S. Food and Drug Administration in 2014 for individuals to use at home. VA officials told The Associated Press that the agency sent a memorandum Dec. 10 outlining its plans to train staff to be able to provide the ReWalk.

“The research support and effort to provide eligible veterans with paralysis an exoskeleton for home use is a historic move on the part of the VA because it represents a paradigm shift in the approach to rehabilitation for persons with paralysis,” said Dr. Ann Spungen, who led VA research on the system.

The company, ReWalk Robotics, said it has evaluated 45 paralyzed veterans who meet the height and weight requirements for the technology — which consists of leg braces with motion sensors and motorized joints that respond to subtle changes in upper-body movement and shifts in balance.

Gene Laureano, 53, is praying his application for robotic legs will go through soon. The former Army corporal remembers the day he first tried the ReWalk at New York’s James J. Peters VA Medical Center in the Bronx two years ago.

“The tears came down,” said Laureano, who was left paralyzed five years ago after falling off a ladder. “I hadn’t spoken to somebody standing up in so long.”

“I just kept remembering the doctor told me it was impossible for me to walk, and then I crossed that threshold from the impossible to the possible,” he added.

When the study ended, however, so did his ability to walk. He’s been waiting to get the robotic legs ever since.

Paralyzed veterans fired off letters to VA Secretary Robert McDonald this summer.

“I guess people who have been watching the research were very anxious and had expectations this would suddenly happen once FDA approval came out, but we were still building the infrastructure to support this great device,” VA spokesman Jim Connell said.

The ReWalk was invented by Israeli entrepreneur Amit Goffer, who was paralyzed in an accident in 1997. Several competing products that use similar technology — nicknamed “electronic legs” — are also being tested in U.S. rehab hospitals.

None, including the ReWalk, are fast enough or can be worn long enough to replace wheelchairs. VA pilot studies found paraplegics who used the exoskeleton as little as four hours a week for three to five months experienced better bowel and bladder function, reduced back pain, improved sleep and less fatigue.

About 42,000 veterans are paralyzed. Of them, a fraction would meet the requirement for an exoskeleton. The apparatus requires specific height and weight requirements and works for paraplegics but not for quadriplegics. A supportive belt around the patient’s waist keeps the suit in place, and a backpack holds the computer and rechargeable battery. Crutches are used for stability, and the FDA requires an assistant be nearby.

ReWalk Robotics CEO Larry Jasinski said a dozen VA centers are expected to start training staff to provide the system. The program will likely be expanded in the future.

Former Army Sgt. Terry Hannigan, a 62-year-old paralyzed Vietnam veteran, was the first veteran to get the robotic legs as part of a test of the system. She uses them to walk through the mall and shop at the grocery store.

“It definitely is a show stopper, especially in the mall with kids. Some say things like ‘Wow, look at Robocop!’” They ask a lot of questions, but I don’t mind,” Hannigan said.

When she was confined to a wheelchair she said she had to ask people to pass her things out of her reach.

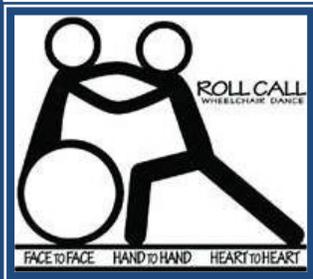
“To be able to hear the conversation, not miss half of what’s being said because it’s over your head, that in itself is a big plus,” she said. “Now I can walk up, shake someone’s hand. I can hug, kiss them. That might be a small thing, but the only other time I would get body contact was when a family member or caregiver would pick me up and put me in bed.”

Author: Julie Watson

Date: December 17, 2015

Photo: <http://bigstory.ap.org/article/aa96a84cf66747ae9d9e4ee1825ed920/apnewsbreak-va-provide-robotic-legs-paralyzed-vets>
[Information Source](#)

At Roll Call Wheelchair Dance, everyone is required to check their egos and disabilities at the door.



“Once you come in the door, you are a dancer,—not a disabled person.” These are just some of the rules Roll Call’s founders John Nyemchek and Diane Discepolo live by to help structure programs that build integrity, confidence and, above all, fun. Together with a talented team of certified wheelchair dance instructors, students are encouraged to share what they can do, not what they can’t. All that is required to join a class is to bring a smile.

Serving mainly the tristate (New York, New Jersey, Connecticut) area, Roll Call Wheelchair Dance teaches people of all ages and abilities how to partner dance with one standing partner and one wheelchair user. Founded in 2011, the program serves almost 200 people a year through bi-monthly classes, special workshops, a dance team, and scheduled performances.

“People with disabilities are not cookie-cutter,” says Nyemchek. “They all have different needs and abilities that range from A to Z. We are constantly revamping our programs to meet our dancers’ needs.”

To help expand the depth and breadth of the program, Roll Call received two Christopher & Dana Reeve Foundation Quality of Life grants: \$5,000 in 2013 and \$7,200 in 2015. With the Reeve Foundation support, Roll Call can cover studio costs and instructor training to teach a variety of dances ranging from the waltz to the jive.

“These generous grants have allowed us to provide the best quality education for programs that would not necessarily be able to exist otherwise,” says Discepolo, who is grateful to get recognition from the Reeve Foundation as a valuable activity worthy of funding. “Adding to quality of life is exactly what these grants do. The program embodies so many aspects that are missing from people’s lives. It feeds the soul.”

Through dance instruction, wheelchair users learn how to manage the chair while concentrating on keeping time to the music. The activity instantly breaks barriers, builds confidence and reduces the sense of social isolation that can impact wheelchair users. Partner dancing promotes trust between the dancer that uses a wheelchair and the standing dancer. Both participants take an active role in what is happening on the dance floor.

“Music is the conversation. It is liberating. It sets the tone and puts everyone in neutral territory,” says Nyemchek. “Every student has a success story. We help them cut the apron strings from their disability and gain a new perspective.”

Over the years, Roll Call has helped several engaged couples with their wedding dances, as well as several father/daughter and mother/son wedding dances. Being able to participate in those special milestones for wheelchair users is priceless. Suddenly everyone is looking at the person, not the chair. That alone is worthy of celebration.

“We never know who is going to come through the door and our professional dance instructors must think outside the box to figure out how to work with all types of people to give them a dance experience that is usable outside the studio walls,” says Discepolo.

Research has shown that dance offers many health benefits, including reduced stress, increased energy, improved strength, and increased muscle tone and coordination—especially of the arms and shoulders. Dance also offers emotional and mental benefits that go way beyond what the organizers could have dreamed.

“Dance does something for a person that no other sport does through touch, eye contact and silent communication,” says Nyemchek. “Within minutes, wheelchair users accustomed to being shied away from everyday are now making close connections. They can experience many different emotions in a safe environment.”

Another unexpected benefit that neither co-founder ever envisioned was the boost to the families and caregivers of the dancers.

“They understand each other and develop positive conversations and connections,” says Discepolo. “Our classes have built an extended family. Best of all, students feel empowered to go on and try other things outside dance class. Dancing is a gift that keeps paying forward—what could be better than that?”

Roll Call’s motto “Hand to Hand, Face to Face, Heart to Heart” says it all.

Article courtesy of :



**Missouri Developmental Disabilities Council,
Scheduled Meetings, Remaining Dates and
Locations for 2017**



**MAY 18-19, HILTON GARDEN INN,
COLUMBIA**

**JULY 20-21, EMBASSY SUITES,
ST. CHARLES**

**SEPTEMBER 21-22, HILTON GARDEN INN,
COLUMBIA**

**NOVEMBER 16-17, HILTON GARDEN INN,
INDEPENDENCE**



Missouri Developmental Disabilities Council under provisions of PL 106-402, the Developmental Disabilities Assistance and Bill of Rights Act

Designed by Charlie Green