

Updated May 22, 2013

August 4 - SUNDAY 9:00 – 10:45 a.m.

Safety, Sexuality and Relationships that Work: Real Talk about Current Issues Facing People with Intellectual and Developmental Disabilities

Speaker(s): *Theresa Fears, Teri Hawthorn, Mary Jo Podgurski*

This hands-on, interactive panel presentation is packed full of helpful tools and practical strategies covering the topics of sexual abuse prevention, sexuality education and supporting people with I/DD to create their own healthy relationships. Participants will hear learn about The Partnership 4 Safety program from The Arc of Spokane, Dr. Podgurski's Me Too! Curriculum (empowering people of all abilities to address sexuality by learning about the topic in an experiential way), and The Arc of Greater Beaumont's practical strategies for parents and family members on how to help their adult child cherish their own sexuality. This session gives you the tools and confidence to honestly talk to people with I/DD about how to protect themselves, enjoy their sexuality and create safe, fulfilling relationships.

The National Effort to Address Dementia and Its Effects on People with Intellectual Disabilities and Their Families

Speaker(s): *Matt Janecki*

This session from the National Task Group on Intellectual Disabilities and Dementia Practices will provide background on U.S. National Plan to Address Alzheimer's Disease as well as the recent work of the National Task Group. The session will cover foundational matters related to dementia and people with intellectual disabilities and their families (such as the causes, screening and assessment, designing programs, and organizing supports) and discuss strategies for chapters of The Arc and families to help anticipate and address the needs of those affected.

Successful Transition Creates Rewarding Employment Opportunities

Speaker(s): *Eric Matthes, Teddy Fitzmaurice, Susan Fitzmaurice, David Taylor, Richard Wilson, Richard Haines*

Self-advocates lead the way towards a full life that includes employment and support services. Learn from this panel of experienced individuals who share a model for transition, ways to advocate for accommodations on the job and how to create business plans for successful a microenterprise.

Fetal Alcohol Spectrum Disorder (FASD): Moving Beyond Prevention to Practical Supports - Part 1

Speaker(s): *Tom Donaldson, Jim Stream, Leigh Ann Davis, Monica Leinberger, Steve Greenspan.*

The Arc has a long, impressive history in the area of prevention of FASD, but as more cases are identified, it is equally important for chapter staff, volunteers, self-advocates and family members to be knowledgeable not only about what FASD is but how it impacts people in the community and why identification and support is critical in preventing secondary conditions of FASD. Learn how your chapter can partner with local agencies, universities and NOFAS affiliates to raise awareness about FASD at the state and local level, provide meaningful advocacy in the educational, legal and criminal justice systems, obtain services for many who are ineligible due to borderline IQ, and encourage self-advocates with FASD to begin their own self-advocacy groups. Learn how your chapter can provide real supports in a life-changing way for families affected by FASD.

Project ACT—A Community Approach to Strengthening Our Cultural Competency

Speaker(s): *Wendy Harris, Alicia Martinez*

Many of us are seeking ways to improve our abilities to serve our increasingly diverse communities. Eight early

intervention programs participated in organizational self-assessments and setting action plans in 2011 using processes which included team building, training, technical assistance, and tools from the National Center for Cultural Competence at Georgetown University. Learn what worked well and what challenges they experienced. Gain resources, tools and ideas to implement your own self-assessment process.

Affordable Housing and Homeownership: New Models in Your Community

Speaker(s): *TJ Sutcliffe, Andrew Sperling, Cathie Griffith*

Learn about two innovative models for housing in your community. First, recent major changes in federal law have modernized the U.S. Department of Housing and Urban Development's Section 811 Supportive Housing for Persons with Disabilities program. Learn more about new options for creating inclusive, affordable housing for people with significant disabilities under Section 811, and how advocates can work with state agencies to make sure their state is ready to compete for federal dollars to make these new options a reality. Second, The Arc of Spokane's Home Ownership Opportunities program helps people navigate the complex process of buying a home by providing individualized counseling and downpayment assistance to qualified candidates. Learn about how self-advocates and families can prepare to live independently in the community and the steps you can take to learn skills that will allow you as a financially responsible adult to purchase a home of your own.

August 4 - SUNDAY 11:00 a.m. – 12:15 p.m.

Update from Washington

Speaker(s): *Marty Ford, Julie Ward, Maureen Fitzgerald, Annie Acosta, TJ Sutcliffe*

Hear from The Arc's Public Policy staff: updates on the latest national disability policy happenings in our nation's capitol. Analysis of the recent budget negotiations and decision and the expected impact on people with disabilities.

Circle of Friends Mentoring Program

Speaker(s): *Kevin Fish, Vonda Bankston*

The Circle of Friends is an innovative mentoring program matching Special Education students with regular education peers, a well-documented need. By developing positive relationships with their peers within their school community, students become more confident, feel more accepted and thrive in school and beyond. It also changes the school culture as students start seeing not the differences, but the similarities we all have. The Arc has developed a program to reach this often times over looked population. Learn how several schools created commercials to highlight their programs which show how their schools are changing. This success led us to an adult mentoring program rolling out in 2013.

Creating Opportunities Starting Profitable Businesses and Retail Products for Your Chapter

Speaker(s): *Mary Lynn Bisland*

Creating sustainable, profitable, and rewarding jobs for people with disabilities is challenging. But in the bayous of south Louisiana, Terrebonne Arc (TARC) has found success in innovative businesses netting over \$1 million in profit in just a few years. Utilizing community partnership, collaboration and support, TARC's businesses, products, and business models can work in your community. Led by Mary Lynn Bisland, whose career in the disability field spans 30 years, has led the change at TARC moving from sheltered workshops to profitable social enterprises. Once solely dependent upon government funding and facing deep budget cuts, TARC founded profitable businesses to ensure financial survival. This

program will provide audiences with a realistic and proven roadmap for creating sustainable businesses that can open in any community. These new businesses will create new skill sets for people with I/DD that will help foster independence and competitive employment.

Fetal Alcohol Spectrum Disorder (FASD): Moving Beyond Prevention to Practical Supports - Part 2

Speaker(s): *Susan Rich, Natalie Novick Brown, William Edwards, Representative from Self-Advocates with FASD in Action (SAFA)*

The Arc has a long, impressive history in the area of prevention of FASD, but as more cases are identified, it is equally important for chapter staff, volunteers, self-advocates and family members to be knowledgeable not only about what FASD is but how it impacts people in the community and why identification and support is critical in preventing secondary conditions of FASD. Learn how your chapter can partner with local agencies, universities and NOFAS affiliates to raise awareness about FASD at the state and local level, provide meaningful advocacy in the educational, legal and criminal justice systems, obtain services for many who are ineligible due to borderline IQ, and encourage self-advocates with FASD to begin their own self-advocacy groups. Learn how your chapter can provide real supports in a life-changing way for families affected by FASD.

Cloud Computing 101

Speaker(s): *Steve McDonell*

By now you have probably heard the term "cloud computing," but do you really know what that means? Find out how moving your information to "the cloud" can transform how your organization operated. Join Steve McDonell, Director of Information Systems at ACHIEVA and the current chair of NCE's Technology and Communications Committee to learn the basics of cloud computing and what it can do to reduce information technology operating costs, improve access to information for staff and ensure the continuity of your business.

We're Not Going To Take It: Stopping Bullying in All Its Forms

Speaker(s): *Amy Goodman and The Arc of Greater Twin Cities*

Bullying comes in many forms and types. Learn about school bullying, cyber bullying, sexting, bullying in the workplace, and three subtypes of bullying that individuals use to attract their victims, manipulative, conditional friendship, and exploitative. Amy Goodman, Co-Director of Autism Now will share statistics and overview of laws related to bullying with emphasis on Autism Spectrum Disorder and bullying. Chapters of The Arc will share highlights of their work in this area as well.

August 4 - SUNDAY 2:30 – 3:45 p.m.

The Arc's Listening Session on Policy, Positions, and Programs

Speaker(s): *Elise McMillan, Michael Mack, Nancy Webster, Marty Ford, Peter Berns*

Join members of The Arc's Board of Directors and staff in a listening session to share your opinions and ideas about the work that we do related to our Position Statements, policies, and programs.

The Arc of Innovation: National Initiatives Leading to Local Success

Speaker(s): *Amy Goodman, Karen Wolf Branigan, Ann Cameron Williams, and Jonathan Lucas*

Learn about The Arc's national programs and the communities they are positively impacting. The wide-ranging initiatives encompass programs to support individuals with Autism through information and referral services: Autism Now and learning the process of flying- from navigating the airport to boarding a plane: Wings for Autism, preventive health and health education services to reduce health disparity and increase longevity and quality of life with individuals with I/DD: HeathMeet, providing post-secondary transition programming for young adults with I/DD: School to Community, and cutting edge electronic recycling enterprises that create integrated employment opportunities for people with I/DD: eXplore eRecycling.

Addressing Institutional Racism: One Organization's Model for Equity -

Speaker(s): *Ilsa Govan, Sylvia Fuerstenberg, Linda Porter, Teresa Barnes*

The Arc of King County is committed the belief that we are better because of our diversity. We strive to address oppression and racism and its effects on the lives of people with intellectual and developmental disabilities, their families and communities. We launched a Racial Equity Team two years ago and hired a consultant from Cultures Connecting, a respected local consulting and training firm on racial equity work. In this workshop, we'll discuss how we gained organizational commitment, established an Equity Team, and implemented plans to increase racial equity. Panel members will discuss what they've learned in this process, including successes and challenges. We'll also talk about community partnerships and programming decisions and give participants resources for starting their own equity teams.

Guardianships and Alternatives to Guardianships for Individuals with I/DD

Speaker(s): *Brian Rubin*

Attorney Brian Rubin, the President of The Arc of Illinois, and parent of a 32-year-old son with Autism, will discuss the who, what, where, why, and how of both Guardianship and "alternatives" to Guardianship, as well as how to find an experienced and knowledgeable attorney in your state. Brian's law practice has been dedicated to special needs planning for 31 years. When an individual with ID/DD turns 18, in most states, parents no longer have any legal authority over their child. Parents find that doctors, health insurance carriers, schools, government agencies, and employers, among others, will not speak with them without authority from their child, or from Court. Are Powers of Attorneys, Representative Payee designations, and health directives the solution? Learn about the "options".

Achieving Momentum through College Inclusion: Person Centered Program of Visual Story Telling

Speaker(s): *James Lawler, David Summers*

This presentation highlights a community engagement inclusion program of AHRC New York City and Pace University that is helping high school high school students and young adults with developmental and intellectual disabilities. University students have been mentoring high schoolers and young adults in the preparation of person-centered planning skills through mobile computing, i-pad, and smart tablet technologies of visual storytelling. The program created a foundation for growth in learning at the university and in society. This presentation will show advocates, family members and professionals how to create chapter inclusion partnerships with local universities and offer simulations of the person-centered technologies of visual storytelling.

Transitioning to Paperless: How Technology Can Improve Care, Maintain Compliance and Reduce Costs

Speaker(s): *Brian White*

This session will discuss the role of emergent technology in supporting people with Developmental Disabilities. Find out how web based, agency / case management platforms are assisting organizations in improving quality of care, maintaining regulatory compliance and eliminating paper. What should you be aware of while making decisions about

transitioning to a paperless agency and what are the most common barriers to the transformation process?

August 5 - MONDAY 9:00 – 10:45 a.m.

MOVE: A Program That Empowers People with Solutions for Mobility

Speaker(s): *Sheila Shegos, Melinda Harrison*

Serving children and adults across the nation, MOVE's philosophy is founded in the belief that "the ability to MOVE is the first foundation stone in building personal dignity". The M.O.V.E.(Mobility Opportunities Via Education/Experience)Program was created to assist students with physical disabilities unable to play with friends at recess. Today, MOVE trains caregivers and assists thousands of individuals by giving them opportunities to participate in meaningful activities (of daily living) to improve mobility skills... to sit, stand, walk and transition. Positive outcomes include better health, more dignity, greater independence and increased inclusion in family and community life. MOVE provides services to individuals with mobility issues; developmental delays, brain injuries, stroke, cerebral palsy, muscular/neurological/orthopedic disorders, joint contractures, and limited range of motion.

Special Needs Trusts Latest Trends - Use of Third Party and First Party Special Needs Trusts to Enhance the Life of Individuals with Disabilities

Speaker(s): *Stephen Dale*

Special Needs Trusts are excellent tools to assist those receiving public benefits. Third Party Special Needs Trusts are typically used by families with a loved one who receives public benefits in order to improve quality of life without affecting benefits qualification. First Party (sometimes called "self-settled") Trusts are used to protect a beneficiary's assets, or perhaps assets received in a settlement or through an inheritance. Which one is best for your situation? This session will review the various options and will include an overview of the latest issues in trust administration. We will cover how a special needs trust can serve as an advocacy tool to provide protection from abuse and neglect by utilizing a care manager. And, we will discuss how trusts can adjust to inevitable changes over the lifetime of a disabled loved one.

Self-Advocacy at Its Best: Replicable Model Programs & Training

Speaker(s): *Adam Shand, Steve Scarton, Pasquale ("Patsy") Ginese, and Jordan Jankus*

People with intellectual and developmental disabilities are at the core of everything The Arc does, because without their voice, really...what's the point? Chapters across the country are engaging and mentoring people with disabilities to become their own advocates in powerful and creative ways - case in point: The Arc of New Mexico and The Self-Advocacy Association of New York. Come learn how these groups are teaching self-advocates about how to create their own self-advocacy groups, develop self-advocacy skills, get a better understanding of disability rights history and have a working knowledge about current topics related to getting the services and supports they rely on. If you've seen one self-advocacy group or curriculum, you haven't seen them all! Don't miss out on this opportunity to take back helpful information that could take your chapter's self-advocacy group or efforts to the next level.

Social Media Fun-01

Speaker(s): *Kevin Wenzel, Amberley Romo*

A basic to intermediate look at Facebook and Twitter, with demonstrations on how chapters can use these common social media platforms to enhance their advocacy efforts, fundraising, brand awareness and communication with supporters and others in their community.

August 5 - MONDAY 11:00 – 12:00 p.m.

Religious Community Inclusion: Making a place for everyone at your Congregation and Religious School

Speaker(s): *Rachel Neimhauser*

In my work as a disability advocate and filmmaker, I have heard first hand how families of people with disabilities find support in their religious communities. As the director of a religious school and the employee of a religious congregation, I also see the challenges and obstacles involved in reaching out to and including people of all abilities. My presentation will be lead by religious leaders/educators of multiple faiths in our community. We will discuss the important role religion can play in the life of a family dealing with disabilities, along with the obligation congregations have to support those families. We will describe the various programs within our congregations that are in place to help and support our congregants with disabilities, as well as the challenges we face when striving to create a fully inclusive environment.

How The Arc's Communication Team Can Help You

Speaker(s): *Kristen McKiernan, Sarah Bal*

What do you do when your chapter is faced with a crisis that is gaining media traction? The first thing you should know is you don't have to face it alone. The Arc's national communications team is available to help you with any media problem - no matter how big or small. We can assist you by quickly drafting press materials, preparing talking points and practicing answers for the media, proofing of press materials, compiling a press list, or even just giving professional feedback on a situation your chapter might be facing. Join us to discuss how we can serve as a resource and hear firsthand from a chapter we assisted this year.

Inclusion Treasures Diversity and Builds Community: The Inclusion Network

Speaker(s): *Stephanie Boyle, Darci Ladwig, Dave Reynolds, JJ Moody*

In 2008 a group of volunteers working through The Arc founded the Inclusion Network (IN), an offshoot of a larger effort to identify key issues facing people with developmental disabilities and their families in Spokane County. The group brainstormed ways to promote greater social inclusion. We remain relevant and effective by not creating programs, but facilitating community interactions and building bridges. We are currently planning our 6th Community Fun Run, a 5k walk/roll/run whose purpose is to bring people with and without disabilities together in an atmosphere of unity and respect. This is not a fundraiser. It is not an outreach event. It is a run that caters to serious, avid runners but creates a welcoming environment for all participants. The Lance Morehouse Jr. Fund for Social Inclusion provides grants to help people with developmental disabilities enjoy socially inclusive activities in the community. To date, we have awarded over 20 grant requests. The accessibility project collaborates with agencies to create a database of disability-friendly businesses in the community so people with disabilities living in Spokane or just visiting can know where to shop, eat or have fun at the click of a mouse. Find out about this and some of the other projects that we are working on such as Inclusive Art, a Small Business Incubator, Community Bakery, inclusion in schools, and a film festival.

Brothers and Sisters of People with Special Needs: Unique Concerns, Unique Opportunities

Speaker(s): *Don Meyer, Jamie Coonts*

Using a lively large-group discussion format, parents, adult siblings, and service providers will learn about the concerns

and opportunities frequently experienced by brothers and sisters of people with special needs. During this workshop, participants share what they have observed in their families of the families they serve. Participants also learn what researchers, clinicians, and siblings themselves say about growing up with siblings who have special needs. An overview of the Sibshop model will be presented and implications for parents and service providers will be discussed throughout the workshop.

Coming Soon: Implementation of the Affordable Care Act

Speaker(s): *Julie Ward*

Learn more about the major provisions of the Affordable Care Act, the progress on implementation and suggestions for helping with enrollment of people who need health insurance coverage.

How to Attract, Involve and Keep Young Members in The Arc

Speaker(s): *Ric Swierat, Sheryl Frishman*

The presentation explores strategies and tools used by a local Chapter of The Arc to attract younger family members to become actively involved in Chapter leadership. This presentation will focus on tools for event marketing, governance involvement, engagement opportunities and structural solutions to bring in new leadership, while honoring the long standing senior leaders in our Chapters. This presentation provides practical applications which are demonstrated through real outcomes at The Arc of Westchester.

August 5 - MONDAY 2:00 - 3:00 p.m.

What Has Medicaid Managed Care Meant to Family Caregivers?

Speaker(s): *Annie Acosta, Maureen Fitzgerald and Heather Williamson*

Individuals with intellectual and developmental disabilities (I/DD) are experiencing longer life expectancies and the majority are living in the community with families acting as primary providers of care. In The Arc's recent national Family and Individual Needs for Disability Supports (FINDS) survey, family members report fatigue, physical strain, financial strain, and stress associated with their caregiving role. Continued increases in Medicaid spending, the primary funding source for family support, future growth and expansion, and tightened budgets have states seeking to save Medicaid dollars by transitioning to a managed care model. Family caregivers in four states were selected as the transition from traditional Medicaid to managed care is well underway or in the implementation phase for all Medicaid recipients. Find out about the research study which assisted The Arc's public policy office in their outreach to policy makers and others to advocate for ongoing family support needs.

Supporting Parents in Supporting their Child to Succeed: Model Programs & Powerful Tools That Work!

Speaker(s): *Magan Cromar, Susan Atkins, Rachel Nemhauser, Jamie Coonts*

Supporting parents in their journey of raising children with intellectual or developmental disabilities is a passion of The Arc, and a role we don't take lightly. This session offers an in-depth look into a grass roots organizational model (called Parent to Parent program) that can help chapters build better and more efficient services and supports for families as they begin the journey of raising a child with disabilities. In this media age, culturally appropriate videos are another important tool that can help parents and families succeed. The Arc of King County will provide a behind the scenes look into the development of videos featuring insights of parents regarding sibling support, parent support and participation in Individual Family Service Plans (or IFSPs). Parents are, and will continue to be, one of the best resources a child has, come learn how you or your chapter can support parents in the ways they need it most.

Know, Grow, and Eat Your Vegetables: Increasing Access to Healthier Foods Among Individuals I/DD

Speaker(s): *Mark Sheenan and Glynnis S. Hunt*

In 2010, Schenectady ARC (SARC) and the Schenectady County Public Health Services (SCPHS) began to address the health risks faced by people with intellectual and developmental disabilities, such as cardiovascular disease, obesity, and diabetes. We collaborated to develop “Know, Grow, and Eat Your Vegetables, Increasing Access to Healthier Foods Among Individuals with Intellectual and Developmental Disabilities.” With a grant from the SCHPS Strategic Alliance for Health and an in-kind donation by SARC, a garden-based nutrition education program for individuals with I/DD was created to increase awareness and consumption of fruits and vegetables through involvement in the growing, harvesting and preparation process. In 2012, the National Association of County and City Health Officials (NACCHO) recognized it as a Model Practice. Learn about the program, the potential for collaboration between chapters of The Arc and local health departments, health disparities and healthy outcomes for people with I/DD, and how NACCHO’s resources can help you reduce health inequities in your population.

Tablets and Apps and Smartphones - Oh my!

Speaker(s): *Hillary Rossi, Jo Ristow, Kelly Johnson, Marsha Threlkeld, Jordan Jankus*

Three groups come together to share the ins and outs of how ipads and other technology can enhance the lives of individuals with disabilities and help your organization stay on the cutting edge of technology.

Medical Education and Health Care: The Role of The Arc in a Unique Partnership

Speaker(s): *Karen Grady, Sweetie Jain, M.D.*

Health care for people with disabilities has been a national issue of concern. Medical professionals also identify this as an area of health care disparity. The Arc of Lehigh and Northampton Counties has developed a partnership with the Medical Home Project of Lehigh Valley Hospital to eliminate the disparities in health care through advocacy and education of health care professionals. Through this unique partnership, The Arc has contributed to the development resources, tools and training programs for patients, their families and physicians in training. This session will provide information on this partnership and the Medical Home model of care for people with disabilities. This model is easily replicable in other areas through partnerships with local primary health care providers and advocacy groups. The session will also provide examples of practice and educational innovations resulting from this partnership.

12 Steps to Recruiting a More Powerful Board

Speaker(s): *Peter Berns*

Building a strong, effective Board doesn’t just happen; it requires a carefully planned, sustained effort. From establishing priorities, to outreach, to elections, board recruitment needs to be an ongoing, year-round process. At this session, you will learn the 12 steps your board development committee needs to take to achieve the result you desire – a dynamic board of directors that advances the mission of your chapter of The Arc.