



The Arc[™]

Pennsylvania

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Pennsylvania Message

THE ARC OF PENNSYLVANIA ANNOUNCES LEADERSHIP CHANGES

Michael Marsh, President of The Arc of Pennsylvania's Board of Directors, announces the selection of Sherri Landis as The Arc of Pennsylvania's new Executive Director. Sherri began her tenure at The Arc of PA on January 7, 2019. Ms. Landis filled the position following the retirement of Maureen Cronin who served 7 years as The Arc of PA's Executive Director.



THE ARC OF PA WELCOMES SHERRI LANDIS

Sherri Landis is the 13th Executive Director of The Arc of Pennsylvania. Sherri's connection to The Arc of Pennsylvania and its 33 local chapters is

extensive. Ms. Landis most recently served as the Executive Director of the DREAM Partnership, a nonprofit organization dedicated to developing a selection of postsecondary educational opportunities, which lead to independent living and employment opportunities for students with intellectual disabilities in Pennsylvania. She was the first Executive Director of this new organization. In this position, she positioned the DREAM Partnership as the leader and voice of postsecondary education, secured grant funds, and led a coalition of stakeholders and state agencies to change internal policies affecting Medicaid waiver funds for postsecondary education. Ms. Landis has served as a lobbyist and her understanding of the Pennsylvania Legislature will be an asset to the work of The Arc of Pennsylvania.

Sherri is excited to lead The Arc of Pennsylvania. "I know that The Arc of Pennsylvania is the leading disability rights

organization in Pennsylvania, and I look forward to our work together as we continue our statewide presence. Throughout The Arc's history, the organization has never wavered on its commitment to advocacy and community inclusion for people with intellectual disabilities. I am excited to work with the Board of Directors, our local chapters, membership, and our dedicated staff to move forward, the rights of people with disabilities and their families," says Sherri.



THE ARC OF PA THANKS MAUREEN CRONIN

The Board of Directors and membership of The Arc of Pennsylvania thank Maureen Cronin for her leadership over the past seven (7) years, during

which she served as The Arc of PA's Executive Director. Maureen was the 12th Executive Director since our founding in 1955. Maureen came to The Arc after serving in a variety of positions within state government. Most recently, she had served as the Director of Pennsylvania's Bureau of Early Intervention Services, administering the state's combined Department of Education Preschool and Department of Human Services Infant/Toddler Early Intervention Programs.



President's Message Michael Marsh



Greetings! I hope that your new year is going well! It is my hope that each of you took a few minutes as the year closed, to reflect on the triumphs and challenges of 2018. Having just enjoyed the holiday season, I'd like to express my gratitude and say THANK YOUS for the many self-advocates, family members, caregivers, and professionals who make every day count. You do the important work of The Arc by getting our message out, advocating for the rights of people with intellectual and developmental disabilities, and providing resources to support families and caregivers. I'm very proud of the work accomplished by The Arc of Pennsylvania and our 33 local chapters across the Commonwealth. We make a difference in the lives of so many people every day. I'd like to highlight a few points in this first President's Message of 2019:

New Leadership at The Arc of PA! We have much to do in 2019 and I am so proud of this organization and our plans for the future! While we sadly say goodbye to Maureen Cronin and thank her for her dedication and leadership over these past 7 years, we look forward to working with Sherri Landis, our new Executive Director. Much has been accomplished under the leadership of Maureen and yet, there is still important work to be done!

This Issue of the PA Message: This edition of The PA Message provides important information on a topic we don't spend a lot of time talking about most days. However, it is a clear and present danger to the physical, mental, and emotional health of the people for whom we care - sexual abuse and sexual violence. Thank you to the professionals and volunteers who have thoughtfully provided articles. This is an area where education and awareness are foundational to making a difference for those who have experienced sexual abuse or violence and helping to reduce the risk of further incidents occurring. Please think of colleagues, friends, or family members who could benefit from reading this or using the resources provided. I sincerely hope that you take time to read and then reflect on the information and resources found in this edition. We appreciate feedback and welcome your comments and suggestions about this issue or topics you think we should cover.

The Arc of PA in 2017-2018: Switching topics for just a minute, I hope that you have seen two recent publications of The Arc of Pennsylvania. The first is the Annual Report which shares data and a summary of what was accomplished in 2017-18. By no means is it a comprehensive list but merely some highlights. Visit our website at www.thearcpa.org ▫ What We Do ▫ The Arc of PA in 2017-2018. You can see the online version of the State of the State Report and our Annual Report. It was also mailed out to government officials, supporters, and

leaders across Pennsylvania, with a letter asking each person to consider making a contribution to The Arc of Pennsylvania in support of the important work we do. I hope that you will also consider making a gift to The Arc of PA in any amount. The important advocacy work, government relations, and education are essential to our mission as is support from members, friends, and families. Thank you in advance for considering how you can show your support.

The Arc of PA's Successful Voting Campaign: Another recent publication highlights the campaign to participate in the 2018 elections. I hope each of you voted and appreciate all of the efforts to get people registered and then to the polls. So many people supported this campaign and you can learn some more about the campaign through The Arc of PA Voting Campaign Results at the same link noted above.

Finally, as we leave the Holiday Season, I want to take this opportunity to thank the many volunteers and staff of The Arc of Pennsylvania and our local chapters for the dedication and thoughtfulness each of you invest in our work. Thank you for sharing your time and your talents. Please accept my best wishes for a joyous New Year!

Sincerely,
Michael J. Marsh,
President of the Board
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Executive Director's Message Maureen Cronin



A FRANK DISCUSSION ON SEXUAL VIOLENCE

The stories of people experiencing sexual assault and sexual violence have been in the news and sexual violence has become part of our everyday conversation. Yet, little is known about the epidemic that exists in the lives of people with disabilities. In January of 2018, National Public Radio (NPR) published a special series called "Abused and Betrayed". This series exposes the sexual assault epidemic that no one talks about. NPR used U.S. Department of Justice statistics that indicate, "The rate of rape and sexual assault against people with intellectual disabilities is more than seven (7) times the rate against people without disabilities. Among women with intellectual disabilities, it is about 12 times the rate." As people with disabilities, parents, advocates, and providers, we must talk about this issue. And we must take action!

A number of factors emerge that make people with disabilities easy targets. We often raise our children with disabilities with a limited sense of control over their own bodies. Having a disability often means being touched by doctors, nurses, therapists, teachers, and caregivers for caregiving reasons. People may need assistance with bathing, dressing, household chores, and in developing relationships. As parents and caregivers,

we tend to teach compliance. Instead, we must teach that saying "NO" is OK. We must start talking about sex and that each person has control over who touches their body.

People with disabilities often don't have a voice. Sometimes people with disabilities can be difficult to understand or they don't use words to communicate. Sometimes the voice they use is not taken seriously. People become easy targets when the perpetrator believes that the person can't tell, or won't tell. Or if they did, no one would believe them. Sexual violence is a crime that goes unreported and unpunished and we must get to the place where it is always reported to the appropriate authorities.

Pennsylvania has a long history of "hiding" people with disabilities. Children attended separate school buildings and separate school classes. People did not work. People lived in large congregate settings. To combat this, The Arc of Pennsylvania has a long history of advocating for the full inclusion of people with disabilities, along with providing the supports necessary for each person to be successful. The Right to Education and the closing of Pennhurst lawsuits are just two examples of our fight for community inclusion. Inclusion changes the view that community has of people with disabilities - from that of a

dependent, passive person to a person with control and a contributor to the life of the community. In fact, we now know that being part of the community reduces risk of harm!

What must we do? We must assure that all people have a voice, including the use of alternative augmentative communication. We must talk about sex and make sure people know they have control over who touches their body. We must report all instances of sexual violence to the authorities. We must support all victims of sexual violence. We must bring this issue out from the shadows and into the limelight. And we must Start Today!

Maureen Cronin
Retiring Executive Director

Statistics Source: Bureau of Justice Statistics, National Crime Victimization Survey, Special Tabulation

Credit: Katie Park/National Public Radio



GO GREEN

The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to: ahouser@thearcpcpa.org to receive your electronic copy.

Inclusive. Dedicated. Determined.

A Goodbye Message From Maureen Cronin

Is it too late to change my mind? All kidding aside, it is hard to leave such a wonderful organization. It has been my extreme honor to serve The Arc of Pennsylvania. While sad to leave, I look forward to joining my husband in retirement. He is a great man who has fully supported me in my wonderful journey with The Arc. Thanks to colleagues, I have wonderful memories. I have enjoyed many good belly laughs which I believe is the sign of a great job. I have been continually inspired by the work of The Arc through our local chapters, state chapter, and at the national level.

I am humbled when I look back at our accomplishments. I am so thankful that every staff person contributed to our amazing accomplishments. Our state chapter has quadrupled in staff size, including having self-advocates in critical staff roles. The passionate staff of The Arc have helped us grow, pivot, change direction; while always positioning The Arc for the next best way to promote inclusion for children and adults with disabilities. Our Include Me program has grown from supporting students in elementary grades to supporting preschoolers all the way through to adults seeking competitive employment. In partnership with Marc Gold & Assoc., we offer cutting edge certifications in Discovery, Job Development, and Systematic Instruction. Our presence and influence continue to grow exponentially. Our social media presence is respected and replicated by other organizations. We are the intellectual and developmental disability 'go to' resource for print, radio, and television media. Our communications are concise and strategic, informing our local chapters and members on key



issues and work happening in government which impacts people with disabilities and their families.

Being your Executive Director, has been a rewarding experience. I have learned so much from our self-advocate leaders, families, and our local chapter staff. I've loved representing The Arc, first and foremost as advocates, but also as providers of services. This combination pushes us to be the best we can be. We have a unique perspective in that we are led by people with disabilities and their families, yet, we know the challenges and possibilities of providing services. I have said many times that I love being part of The Arc movement, knowing I could reach out to any of our chapter execs, knowing how we all support each other, sharing wisdom and resources. I so appreciate all the kindnesses offered by our chapter execs throughout my time at The Arc. Our chapter execs are some of the most dedicated and hardworking leaders I have ever known.

To all the Board of Directors and Board Presidents who are the most devoted of volunteers, I thank you for all your support, goodwill, and faith in my leadership. Know that you have built a steady foundation for future Boards to assure the continuance of our strong state chapter. It is most difficult leaving colleagues, but it is with gratitude that I leave The Arc and I wish our new Executive Director, Sherri Landis the very best. The search committee and Board of Directors made an excellent choice. I know that you will all love Sherri and I am excited to see where Sherri leads The Arc next. I will always care deeply for The Arc and I am excited to see all that you accomplish in the years to come.



Your Voice Matters



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SEXUAL ABUSE AFFECTS US ALL

Addressing and Preventing Sexual Violence is for Everyone

By: Kayla Houser, Outreach Coordinator, Pennsylvania Coalition Against Rape & Dee*, Pennsylvania Resident

The #MeToo Movement has propelled the often hidden topic of sexual violence into public discussion. Despite this, we know that sexual abuse and harassment still occurs every day and many survivors still feel unsafe to disclose their abuse. The #MeToo Movement has focused on some survivors more than others—we know that many voices, including survivors with disabilities are still left unheard.

The trauma of sexual violence may leave a lasting impact on survivors, their family, and even the community. This is why it's on all of us to respond to and prevent sexual violence. What we say and do about sexual violence matters to people with disabilities and those that care about them.



Dee* is a survivor!

When Dee* met Daniel, “he really seemed like a nice guy”, she said. “He showered me with gifts and attention and told me how beautiful I was.” Little did I know this was not the person he really was. I started getting suspicious when he wouldn’t stop texting while we were on dates and he started doing things that would embarrass me in public. Like he would come out of the bathroom with his pants unzipped or fart at public events.

What You Can Do

Raise awareness of this epidemic. Talk to other people about this important issue.

Nurture healthy sexuality by:

- o Answering questions accurately
- o Recognizing and reinforcing positive interactions
- o Providing information about the body and sexuality

Promote clear and open communication

Connect with your local Rape Crisis Center & invite them to learn more about the disability movement.

TERMS USED:

Throughout this document, the terms “*victim*” and “*survivor*” are used interchangeably and are inclusive of the various ways people who have experienced sexual violence may identify. The Pennsylvania Coalition Against Rape (PCAR) and National Sexual Violence Resource Center (NSVRC) recognizes and supports the use of person-first terminology that honors and respects the whole person, which is also reflected in this document. Finally, we acknowledge that individuals should ultimately choose the language that is used to describe their experiences and therefore, we support advocacy approaches that are person-centered and that use the terminology preferred by individuals they serve.

PEOPLE WITH DISABILITIES AT INCREASED RISK FOR VICTIMIZATION

Sexual violence is a serious and widespread problem in all communities; however, people with disabilities are at an increased risk for victimization. The National Intimate Partner and Sexual Violence Survey found that, in the U.S., one in three women and one in six men experienced some form of contact sexual violence in their lifetime (Smith, 2017). People with intellectual disabilities are sexually assaulted at a rate seven times higher than those without disabilities (Shapiro, 2018). Perpetrators often target those who they believe won't share what's happened to them, and if they do, won't be believed. People with disabilities may be targeted for a number of reasons: 1) increased isolation, 2) having non-traditional communication methods, or 3) differing cognitive or physical abilities. Often a survivor with a disability may not be believed by those they tell due to misconceptions about people with disabilities as "reliable witnesses" or their ability to understand what's happened to them.

WHAT IS SEXUAL VIOLENCE?

By increasing the understanding of the issue, we can more effectively address and ultimately prevent sexual violence. Sexual violence includes any type of unwanted sexual contact, including:

- ✓ Words and actions of a sexual nature
- ✓ Rape
- ✓ Incest
- ✓ Child sexual abuse
- ✓ Sexual violence that's committed in an intimate relationship
- ✓ Sexual exploitation
- ✓ Human trafficking
- ✓ Unwanted sexual contact, which includes unwanted touching of genitals either under or over clothing
- ✓ Sexual harassment, which can include unwanted comments of a sexual nature about someone's body or sexual acts
- ✓ Unwanted exposure of someone's genitals
- ✓ Forced viewing of pornography
- ✓ Voyeurism, which is unwanted viewing of someone with or without their knowledge.

Those who commit sexual harm are often people who we may love, know, and trust, which can make it even more challenging for a victim to tell someone what's happened to them. For people with disabilities, it may be a caregiver - someone who is paid or unpaid to provide needed personal care and/or guidance.



After his sister's wedding, everything really changed. I found objects from other women in his car and in his apartment. When I would go to visit, he told me that the TV in the living room was broken, so if we wanted to watch movies, we had to watch in his bedroom. I tried to sit on the floor, and he pressed me to sit on his bed. He then started to hold me down and tried to have sex with me. Once we went to his dad's house. Going up the steps, his father touched me on my rear end. I didn't know what to do.

SEXUAL VIOLENCE IS ABOUT POWER AND CONTROL

Sexual violence is about power and control, not about sex. Perpetrators choose when, where, how, and who they will harm.

A person committing sexual violence may also use:

- ✓ Direct or implied threats of harm or to harm someone else, to withhold basic needs, or to restrict access to needs;
- ✓ Social Manipulation, such as utilizing a friendship or relationship to gain trust, promises of special treatment or rewards, making the person believe this is a normal part of a relationship; and
- ✓ Coercion, which can look like using their power (power can be official power, or power in that they are responsible for someone's daily care), repeatedly asking someone for sexual acts, making the victim believe it was their fault, using shame and guilt to obtain compliance, using drugs or alcohol to obtain consent.



When he would force me to have sex, I felt lost, like being in a really dark place. I wanted to be his girlfriend. I thought we had a good relationship. He did things with my parents and I, and I always helped him out, like helping him keep his apartment clean. I bought him things for his apartment, especially during the time that he lost his job.

I never told anyone what was happening. I did not tell my friends, not even my mother. My mother knew something was wrong because I was always holding my head down and not making eye contact. I didn't want to socialize with my friends and my seizures increased. And she wondered why I never wanted to be alone with Daniel anymore.

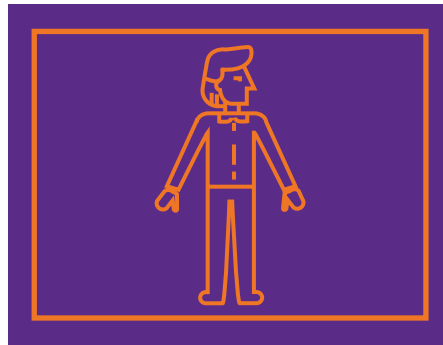
It wasn't until the stress got so bad and my seizures were so out of control, that my mom learned what was happening. I had told my doctor about the ongoing abuse in the relationship and together we told my mother. I was diagnosed with Post Traumatic Stress Disorder. I now realize that I buried all this so deep. I was ashamed and believed that I caused this to happen. I believed I could not tell anyone.

THE IMPACT OF SEXUAL VIOLENCE

Sexual violence impacts victims, families, and communities. Each survivor reacts to sexual violence in their own unique way. There are long-term and short-term impacts of sexual violence on overall health and well-being. Survivors with intellectual and developmental disabilities are impacted by traumatic events similarly to people without disabilities.



Common emotional reactions include guilt, shame, fear, numbness, shock, and feelings of isolation. This may include changes in behavior, unexplained fear or anger, or even what care providers may view as “acting out.” It's important that we recognize these as potential signs of trauma and not as “behavioral issues.”



Some physical signs of sexual abuse can include unexplained pregnancy, acquired sexually transmitted infections, increased urinary tract infections, bruises, lacerations and other physical injuries. Psychosomatic symptoms often occur, such as stomachaches, headaches, seizures, and problems with sleeping.

? ? WHAT TO DO ? ?

If you are unsure what do, begin by believing survivors and assisting them in finding resources. This can be a first step in healing for a survivor and a way to change our culture to prevent future sexual violence.

Prevention is possible, is happening, and is everyone's responsibility. In addition to arming ourselves with ways to reduce the rates of sexual violence, we can also work to create a culture that prevents sexual violence from happening in the first place. We all have a role to play in creating safe environments. The Centers for Disease Control found that building skills to solve conflict through dialogue, increasing emotional health and connectedness, involvement in school and work, and building cultures of empathy can reduce the likelihood for the perpetration of sexual violence (CDC, 2018).

It's important that we also support people in learning how to have body autonomy and how to report sexual abuse. We can learn to be active bystanders by addressing problematic behaviors when we see it. To support others and ourselves in speaking up, we must promote and model healthy boundaries, respect, promote body autonomy, and build a culture of consent, not just in relation to sexual experiences, but in our everyday lives.

HELP IS AVAILABLE

If you or someone you know is a victim or survivor of sexual violence, help is available no matter when the abuse occurred. The Pennsylvania Coalition Against Rape works with a network of rape crisis centers throughout Pennsylvania that provide free and confidential services. To find a center near you, please visit www.pcar.org/help-in-pa or call 1-888-772-7227.

Kayla Houser is the Outreach Coordinator at the Pennsylvania Coalition Against Rape. She can be reached at knhouser@pcar.org or at 1-888-772-7227. Dee (not her real name) lives in Pennsylvania.*

Centers for Disease Control. (2018, April 10) Sexual Violence: Risk and Protective Factors. Retrieved from CDC: <https://www.cdc.gov/violenceprevention/sexualviolence/riskprotectivefactors.html> .

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I continue to deal with what has happened and while things are better, I still struggle. Daniel continues to stalk and follow me around. Sometimes I get threatening phone calls as he uses phones that belong to other people. My mom helped me connect with the local Rape Crisis Center in my town. They are helping me understand that what happened was not my fault. In my counseling sessions, I am learning how to meditate and how to use relaxation strategies to relieve stress.

I now know that by not telling, the anger really built up inside me. What I cherished most about myself, my pride and my dignity were gone.

If you are a victim of sexual violence, you need to tell someone. You need to speak up for yourself. Tell a person that you trust; a person who you know loves you. Don't hide it! If you hide it, it will get worse. Remember, this is not your fault! Remember that your local Rape Crisis Center can help you. By calling, they will help you contact the police. If you have been raped, they will tell you not to shower so that evidence can be collected. They can help you figure out what happened and will support you in moving forward - in being a survivor!

HELP • HOPE • HEALING

The Pennsylvania Coalition Against Rape (PCAR) values our ongoing partnership with The Arc of PA. Although the word “rape” is in our name, our network of centers serving all 67 PA counties, provides resources and support for all types of sexual violence - child sexual abuse, human trafficking, sexual harassment, sexual assault, etc. Our centers use a trauma-informed individualized approach and are flexible to make our unique services accessible to people with disabilities and all survivors and their families and support systems. We serve all ages, genders, and abilities. Many centers offer services in multiple locations and can travel to meet with people in a variety of settings. Center locations are available on our website at www.pcar.org.

Karen Baker, CEO, National Sexual Violence Resource Center/Pennsylvania Coalition Against Rape. She is located at 2101 N Front Street, Governor’s Plaza North, Bldg. #2, Harrisburg, PA 17110. For more information, Ms. Baker can be reached at 717.728.9740 x101; 800.692.7445 Toll Free; kbaker@pcar.org .

Call 1-888-772-7227 to reach your local rape crisis center.

www.pcar.org ⇔ www.nsvrc.org

ENDING SEXUAL VIOLENCE AGAINST PEOPLE WITH DISABILITIES: SEX EDUCATION IS PART OF THE SOLUTION

Just saying “Don’t Have Sex” is not the answer!

Traditional approaches to ending the epidemic of sexual assault against people with intellectual disabilities have not worked. These approaches are often narrow in scope and emphasize a fear perspective. Instead, we must address how friendships develop, evolve, and even end. According to Chitra Panjabi, President & CEO, Sexuality Information & Education Council of the United States (SIECUS), “to ensure sexual health, a comprehensive approach is critical - one that normalizes sexuality, addresses key barriers, and equips people with the information they need.” People with disabilities want fulfilling relationships, companionships, friendships with both sexes, and marriage - just like people without disabilities!

Sexual expression is a natural and central aspect of being human. It is the interconnection between the extent to which human rights are respected, protected, and fulfilled. The last 40 years has ushered in a new paradigm of change within the disability movement. Disability philosophy and ideology now

Comprehensive sex education is essential!

Education is a proactive strategy for reducing sexual violence and should include information about:

- ✓ Your Body
- ✓ Your Sexual Orientation
- ✓ Your Sexual Rights & Responsibilities
- ✓ The Importance of Consent

promote person-centered planning, self-determination, inclusivity, and the rights and responsibilities of people with disabilities to live an everyday life. An everyday life includes a sexual life. Depending on what “chair” you are sitting in - parent, provider agency staff, administrator, support coordinator, or other allied/professional position, your vision of a sexual life might look different from that of the person you are supporting. Sexual lives are fluid. They change over time. No two are exactly alike or have the exact same meaning to both people.





UNDERSTANDING SEXUAL NUANCES

One important area of comprehensive sex education that is often overlooked are sexual nuances. Sexual nuances are subtle distinctions that often go unnoticed by family members, educators, and professionals, especially when developing an Individualized Education Program (IEP), Individualized Service Plan (ISP), or Individualized Health Plan (IHP). Sexual nuances are overlooked because they are not included in educational curricula or talked about with family and friends.

Students without disabilities generally understand boundaries and the consequences these behaviors present if done in a different environment toward a non-team member. However, for James*, no one informed him that after practice and after games, that locker-room behavior is not appropriate in other settings such as gym class, a visit to the YMCA, or other public or private athletic clubs.

Engaging in “locker room” behaviors in other settings could look quite differently. The recipient of such behavior could be alarmed, scared, and even consider telling staff or calling the police. What one person considers “playful butt smack,” someone else may consider harassment or even abuse. Conversations concerning sexual nuances, such as locker room behavior, need to be a regular part of the team’s orientation for all players, not just for athletes with disabilities. Conversations should be clear and concrete, avoiding generalizations, and using non-judgmental words and body language.

Another example of sexual nuance is how the word “friend” can be used to blur the lines between friendship, dating, predatory grooming behavior (making an emotional or “friendship” connection as a set-up for abuse), and manipulation.

“To ensure sexual health, a comprehensive approach is critical- one that normalizes sexuality, addresses key barriers, and equips people with the information they need.”

- Chitra Panjabi, President & CEO, Sexuality Information & Education Council of the United States



James

James, a male high school student with Down syndrome, made the football team. He and his family were excited for the opportunities that playing on a sport team provides - the comradery of being part of a team, experiencing and learning how to manage the highs and lows of winning and losing, building friendships, and being “one of the guys.” It all seemed so straight forward and positive - a notable example of self-determination and inclusion. For players, it is typical for adolescent and adult athletes to engage in certain locker-room behaviors such as a chest bump, towel snaps against another team member’s bare backside, and playful slapping of each other as a way of saying “well done,” “great play,” “way to go,” etc. Physical contact of this type is considered part of team-bonding and team-culture. It is a regular part of high school, college, and professional sports locker room behavior.*



Yvette

Twenty-year old Yvette*, is a woman with an intellectual disability and autism. She works evenings at a clothing store in the local mall. She travels back and forth to work using public transportation. There are very few people on the bus when she gets on at the end of her work shift. One night the bus driver offered to drop her off at a bus stop closer to her home. However, he told her she would have to stay on the bus until everyone else got off and then he would drop her off close to her house on his way back to the bus terminal. She agreed. He makes the same offer on the following evenings. He told her, “This is what friends do for each other” and “Such a pretty girl should be careful walking home at night.” Each evening he compliments her. He tells her how pretty she is, how special she is, and how lucky he is to be her friend. Having gained her trust, one night when she was getting off the bus, he asks her for a goodnight kiss. He said it was okay because, “that’s what friends do.” She liked the attention. She liked the kiss. She liked getting off the bus closer to her home and she liked the thought of having a boyfriend. The kiss evolved into fondling and eventually sex in the back of the bus.

One night she said no. She said she did not want to have sex on the bus any more. He told her “It was their special place - their secret.” When she continued to resist, he told her he would no longer be her friend and he would no longer be able to drop her off at the bus stop closest to her home.

Yvette works part time and lives in her own apartment. She wants to be like the other young women she works with. Her co-workers have boyfriends. They go out after work for drinks and have consensual sex. Yvette was afraid that if she told her parents about what was happening on the bus, they would pressure her to move back into the family home. She was afraid that if she told her staff or co-workers, they would call the police. She decided to tell no one. Afraid of the bus driver, she quit her job, became reluctant to take other forms of public transportation, stayed in her apartment, and blamed herself for what happened.

IT COULD HAVE BEEN DIFFERENT

Yvette’s situation could have had a different outcome had Yvette had the opportunity to talk with her parents and staff about relationships, saying “no”, the importance of asking questions, and telling someone if you’re uncomfortable in a situation. Discussions about friendships, flirting, dating, abuse, and manipulation are all pro-active steps in reducing sexual victimization.

We live in a society bombarded with sexualized images and messages, and yet as a society we are reticent to talk about healthy sexuality. When we shift our thinking to include looking at how social norms and sexual nuances are taught and then experienced by individuals with intellectual disabilities and autism, we reduce the risk of them becoming involved with the criminal justice system as victims, suspects, and defendants. By creating and sharing this knowledge, systems are changed, self-determination is promoted, and disability and sexuality are recognized as a natural part of the human experience.

**Pseudonyms*

Beverly L. Frantz is the project director for the criminal justice and sexuality initiatives at the Institute on Disabilities at Temple University. Dr. Frantz focuses her work on the intersection of disability, healthy sexuality, sexual violence, criminal justice, and the judiciary system. Contact Dr. Frantz at bfrantz@temple.edu .



A MOTHER'S "AHA" MOMENT: TEACHING BOUNDARIES & RESPECT TO MY DAUGHTER

We all demand our personal space. Even at a young age, I can remember my brothers and I bickering back and forth about our space. We'd say, "he's touching me" or they'd say, "she's in my space". When my space was invaded as a child, it was more of an annoyance than a serious violation of my body and personal space. Nowadays, stories abound where people with disabilities have been violated. Understanding this issue and establishing boundaries is important as we work to reduce the risks and reduce the incidences of sexual violence.

My perspective changed when I became mother to a teenager

As a mother of two children, one with significant support needs, I insist that people respect their personal space. Sophia, my oldest, lives with significant disabilities and requires round the clock care. Sophia's disability affects her gross and fine motor skills in all parts of her body. She is difficult to understand, and she has developmental and cognitive delays. As she got older, she required nursing staff to support her. I am no longer the only one to bath, toilet, and change her. It was during this time that I began hearing and seeing a change in her. She started to demand her independence. Sophia would say, "I do it, you no worry 'bout me!"

A Mother's Aha Moment

I recently attended a series of workshops facilitated by Dr. Mary Jo Podgorski. She developed two curriculums, one called "Me Too" and one called "Inside Out". These curriculums teach families and professionals a body positive, affirming, and empowering way to approach sensitive topics on sexual health, abuse prevention, and self-awareness with young people. We discussed boundaries and how as family members, providers, and caregivers, we teach people with disabilities to be compliant to anyone who offers them support. And we learned how this increases a person's risk for sexual assault!

Our conversations during the workshop became tense and emotional as Dr. Mary Jo shared true stories where children were taken advantage and/or sexually assaulted. In those instances, sometimes it was ignored; not recognized as a violation of the person's

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body. In each instance, the person did not understand that their body belonged to them. They did not understand they had a right to be safe. They did not understand the need to be asked before being supported by people they chose and trusted.

That's when it hit me - and I mean to the core! As Sophia's mother, I never once stopped to think about this from her perspective. I considered Sophia safe and happy, because she had a nurse that I respected. I thought of times when the nurse would try to get Sophia to go to the school bathroom like the rest of her class at 9:00 a.m. This was before her next class and it always ended up with Sophia having a complete meltdown. So, what did we do? We created a Behavior Plan!

I started to think... if I was paralyzed and someone I didn't know was moving me out of my chair and I didn't want to move, I'd have no recourse but to kick and scream. Even if they put me down, I still could not move on my own and would not even be sure people were paying attention to me as I said "NO" in whatever way I could.

I realized then that we were not respecting Sophia's desire to have control over her own body. We were not giving her the respect she deserves. We underestimated her ability to know her own body. Never once did it cross my mind that she might not actually have to use the bathroom. What about a bath? Can you get any more intimate than that? Oh, and wait, your usual nurse is not coming, but this other one is a "nice lady". She will bath you, wipe you, and dress you. Just do what she says and "be good" was the message we sent her. Why was I expecting my daughter to be OK with people crossing her boundaries? Why was I OK with people having access to her body in a way that left her helpless and vulnerable? The day I got home from this workshop, I told Sophia and her staff that from now on, we will ask Sophia if we can touch her as we provide her care.

We removed her "behavior plan" from her IEP and our life. We were being hypocritical when, on one hand, we preached "behavior is communication", but then we would create a plan to eliminate that particular behavior. When I have a "behavior" towards my husband, it's because I feel he is not hearing me or acknowledging what I am expressing. As much as he'd love to, he does not grab a notebook and start creating a plan. He works on listening and hearing me. That is what we needed to start doing with Sophia. I would ask her, "Can you tell me (any way she could) what you are feeling?" In time, Sophia found a way to express to us when she had a need, such as when she needed to use the bathroom.

A new way of providing support emerged

When Sophia tells us she needs to use the bathroom, we explain exactly what we are doing. We ask her permission to take her pants off so that she can use the toilet. We ask her "Are you ready for me to wipe and clean you?" This simple communication between Sophia and her caregiver has made their time together a bit smoother. But, most importantly, it has taught Sophia that she matters. It proves to her that what she says and feels matters to us. Not just anyone can touch her. As her mother, I can't protect her 24 hours a day, but I can arm her with knowledge that can reduce her vulnerability.

Authors: *Sophia Butler is in 11th grade. She enjoys music, cooking, taking classes in agriculture and is involved in 4-H. Lisa Butler is the mother of two teenage children. Sophia has significant support needs and receives services from the home and community based service system. Lisa is a Manager with The Arc of PA's Include Me Project. She can be reached at lbutler@includemepa.org.*

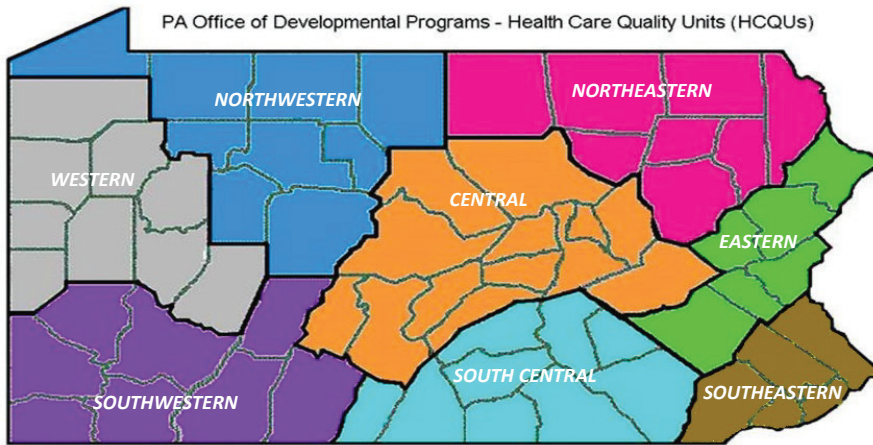
For more information about the Me Too or Inside Out Curriculum, visit Dr. Mary Jo Podgurski's website at: <http://drmaryjopodgurski.com/>. Dr. Mary Jo Podgurski's life work is serving young people and their families. She has a background in nursing, education, and counseling; and she is certified in sexuality education and sexuality counseling.

LEARN MORE DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at pie@thearcpa.org to receive electronic alerts and the quarterly newsletter.

HEALTH CARE QUALITY UNIT (HCQU) - LOCAL SUPPORT FOR THE DISABILITY COMMUNITY



◆ Central PA HCQU - Geisinger	◆ Northwestern PA HCQU - Milestone	◆ Southwestern PA HCQU - KEPRO
◆ Eastern PA HCQU - The Advocacy Alliance	◆ South Central PA HCQU - The Advocacy Alliance	◆ Western PA HCQU - Milestone West
◆ Northeastern PA HCQU - The Advocacy Alliance	◆ Southeastern PA HCQU - Philadelphia Coordinated Health Care (PCHC)	

- ✓ Offer trainings (either face-to-face or web-based), including information and training on Sexual Health, Healthy Relationships, and Prevention of Sexual Violence
- ✓ Review medical records and make recommendations for health and safety
- ✓ Review behavioral health plans and provide recommendations for health and safety
- ✓ Identify appropriate resources to the individuals directly or to those who support them

Who can get services from the HCQU?

Any adult with an intellectual and/or developmental disability who is receiving home and community based services, as well as their family, or support staff, are eligible to receive services by the HCQU. The HCQU does not provide any hands-on teaching or treatments. There is NO COST for these services.

In 1997, the Office of Developmental Programs (ODP) created a statewide program to promote capacity building within the Intellectual Disability (ID) provider and health care communities. Eight (8) Health Care Quality Units (HCQU) were established and operate regionally throughout Pennsylvania.

What is the HCQUs role in Reducing Risk in the Epidemic of Sexual Violence & People with Disabilities?

The HCQU’s role is to support individuals, families, and providers in understanding the importance of sharing accurate sexual health and relationship information with individuals having disabilities. Adults with disabilities have all of the same rights to relationships that adults without disabilities have. And all too often, individuals receiving home and community based services find out what a healthy relationship is, only after something negative has occurred. With proper education about relationships, we can reduce the risk of negative situations occurring. Ask yourself: How do you know if you are in a healthy relationship if you don’t know what a healthy relationship looks like and feels like? This is where education is vital. HCQUs across the state offer training and information on this important topic.

What is the role of the HCQU?

The nurses and behavioral health coordinators that staff the HCQUs support the adult intellectual and developmental disability community. HCQU staff can provide support in a variety of ways:

How do I access services?

Contact your supports coordinator (SC). Your SC will reach out to the HCQU to initiate services.

How important is this issue?

HCQUs base their work on the Everyday Lives value statements. By avoiding the topic of sexuality, we often set individuals up for failure by neglecting to provide much needed and much deserved education. Some folks think that if we provide sexuality education, that we are “planting” ideas in people’s heads to be sexually active. The risk of not providing accurate information is that individuals may never have the opportunity for a fulfilling and meaningful relationship that is safe, healthy, and satisfying. Proper education can reduce the risk of disease, unwanted pregnancy, exploitation, and abuse. Accurate information and education can also increase self-esteem, acceptance, empowerment, and overall well-being.

ODP (Office of Developmental Programs) recently issued a set of guidelines on the topics of sexual health, personal relationships, and sexuality. The guidelines emphasize that Individuals with disabilities have the right to have their sexual health and personal relationships supported by knowledgeable provider agency staff and a knowledgeable

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individual support plan team. Education and accurate information are important to all individuals, and it is important to have a support team that is educated with accurate information, so they provide the best support possible.

Laura Dadswell, MS, BSL, Behavioral Health Coordinator, The Advocacy Alliance, South Central Health Care Quality Unit

Visit www.MyODP.org to find more information about HCQUs.



Everyday Lives: Values in Action is a guide to the Office of Developmental Programs (ODP) as it develops policy and designs programs. Providers of services use these recommendations to support individuals and their families to achieve everyday lives. For more information about Everyday Lives, visit www.MyODP.org.

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LET'S TALK: SEXUAL ABUSE AWARENESS

Let's Talk: Sexual Abuse Awareness is an interactive peer discussion led by Power Coaches, self-advocate presenters, and facilitators. During the conversation, we talk about the real names of body parts and sex. We discuss what consent is - and what it isn't. People learn about abuse - who can be abused? And who can be abusers? We talk about saying NO, telling, and reporting. We share the stories of survivors - people who used their experience to help others. Each event is about 3 hours long with regular breaks, and includes one or more counselors from a local rape crisis center.

Call (724) 588 2378 or email us at info@sau1.org today to schedule an event in your area.

Let's fight the epidemic together.

SAPNA, The Self-Advocacy Power Network for All is a project of Self Advocates United as 1, funded by the Pennsylvania Office of Developmental Programs to empower self-advocates through sharing knowledge and personal experience.



RESOURCES

LEARN MORE

Pennsylvania Coalition Against Rape (PCAR) - A Guide for Friends, Family & Care Providers of Sexual Violence Survivors Who Have Disabilities - www.pcar.org .

Pennsylvania Coalition Against Rape (PCAR) - County Specific Resources - <http://www.pcar.org/help-pa/locations>.

The Brain, Body, and Trauma (e-learning course) from The National Sexual Violence Resource Center - <https://www.nsvrc.org/elearning/12554> .

Beyond the Birds and the Bees: Adolescent Sexual Consent & Disabilities: A Technical Guide - email alivelsberger@pcar.org for a copy.

Abused & Betrayed Series: <https://www.npr.org/series/575502633/abused-and-betrayed>

Smart Talk: "Epidemic of sexual assaults on people with intellectual disabilities" Written by Scott LaMar, Smart Talk Host/Executive Producer | Jan 17, 2018

The Arc and 1in6 Partner - Promoting Survivors of Sexual Assault in All Communities, a national nonprofit organization supporting men who have experienced sexual abuse or assault. <https://medium.com/sexual-assault-awareness-month-2018/metoo-survivors-with-disabilities-we-will-not-be-forgotten-2e075e7098a8>

Responding to Survivors with Autism Spectrum Disorders: An Overview for Sexual Assault Advocates, which is now available online. <https://www.nsvrc.org/responding-survivors-autism-spectrum-disorders-overview-sexual-assault-advocates>



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Save the Date

The Arc of Pennsylvania
Advocacy & Policy
Conference 2019

June 10th & June 11th

Annual Membership
Meeting

Monday, June 10th

Legislative Breakfast
Disability Funding Rally
Plenary Sessions

The Power of Technology:
Inclusion, Participation, Making it Happen!

Tuesday, June 11th

Watch for more details!

MISSION STATEMENT

The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.