DisabilityIssues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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The PCA Who Raped Me

Name withheld

Being in my 30s and having been happily married for several years, I never thought I would have shared trauma with so many young women who experience date rape and the resulting cocktail of troubled, mixed emotions. But here is my story:

The paralyzing auto accident had upended our carefree lives. My loving spouse soon wearied of the level of care I needed at home after discharge from months of hospital rehab and eventually filed for a no-fault divorce, begging me to understand the daunting prospect of a lifetime of caregiving.

I was devastated but determined to survive all this, even though I felt terribly hurt and vulnerable. Luckily I had the house and interim family care while I got back on my feet, metaphorically. And my employer, a local company, had reinstated me in my professional position. New to the personal care assistance (PCA) scene, I ran an ad in the local newspaper that yielded no viable candidates. Diversifying my recruitment methods in an amateur way, I posted a Help Wanted flyer on the corporate bulletin board near the cafeteria. It offered weekly cash and a rent-free room in my house, which was nearby.



Self-Defense and People with Disabilities

by Sandy Alissa Novack

he first self-defense class I attended was offered by my town's police department. I asked multiple questions in advance about their experience of having people with disabilities in previous classes. The answer was encouraging,

so I signed up for it. The policemen doing the training had a large class. Most of the participants (all women) seemed to be much younger than me and the majority seemed to be flexible, nimble, speedy, coordinated, athletic, and able to follow the policemen's directions easily. One policeman took me briefly aside to brainstorm self-defense measures given my abilities and disabilities, but I could have used more of that. I was given the R.A.D. (Rape.Agression.Defense.) Basic Physical Defense for Women Participant Manual. I was able to appreciate some of the material in it that had been discussed on Day One of the training. The course, however, was not the best match for me, but that is not to say that if your town offers such a training for women you should not go to try it; it may be a great match for you and your own situation.

Next, I read about and signed up for **IMPACT–Boston**'s one day combined self-defense and creative writing class. When I entered the classroom, I immediately felt comfortable when the instructor asked me questions about my abilities and disabilities, then began formulating her thoughts on adapting approaches and techniques to my functional abilities. It was a much smaller class than the police training had been and each "student" got more individual attention about details of foot placement, etc. Interspersed between practicing self-defense, we were given prompts to get our creative writing juices flowing. We were invited to read what we wrote out loud to the group, if we wanted to. As a lover of writing, this approach truly was a great match for me. Both the instructor and the model attacker had solid self-defense techniques and were especially attuned to adapting techniques to each person's particular abilities. Class members all agreed that reflection on practicing self-defense moves and then writing about it helped raise confidence, was empowering, and helped solidify what we were learning. I came home with a practical and adapted-for-me

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self-defense mind-set. I felt very positive about the experience.

Fast forward to more recently, when IMPACT offered the self-defense and creative writing class again but in a longer, two-day format; both men and women were in the class. Why go again? Because like many things in life, you have to practice self-defense to be ready to use what you learned when the need arises. A number of people in the class shared that they have taken a variety of IMPACT's classes to address their own reasons for learning self-defense.

If you think it would not be possible for you to go to a self-defense class, think again. IMPACT has thought this through. For example, in my class one of the first things the instructor told us was that if any of us felt overwhelmed while writing because of past trauma to self or loved ones, we should ground ourselves and write "I feel my feet on the ground, I feel my back against the chair" or write a list about what makes you feel calm, soothed and good. On the other hand, if you feel you can't possibly protect yourself physically because of your disability, you may be overlooking an ability you have that, with the right technique and practice, would help you get away from an attacker. For instance, if you have the capacity to yell, yell. Your loud yell could bring attention to your situation; attention the attacker does not want. In essence, I am not saying that you need to become an Olympian in self-defense. But hopefully



IMPACT is part of Triangle, an organization that empowers people with disabilities to find employment and pursue their goals. As an abuse prevention program embedded in a disability service agency, IMPACT is committed to creating safe and healthy communities for people of all abilities.

IMPACT:Ability is a comprehensive, organization-wide approach to abuse prevention. It combines changes in official policies with efforts to create an organizational culture that challenges abuse and bullying while supporting self-advocacy, choice, and healthy sexuality.

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- Official policies that protect people who report suspected abuse, provide clear direction for how to respond to abuse reports, and clearly define safe and healthy interactions.
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- Abuse Prevention Leadership Teams that support an organizational culture that prevents abuse.
- Self-Defense & Self-Advocacy Education for people with disabilities so they can be central to their own safety.

Our trainers are also available for stand-alone self-defense classes for people with disabilities or abuse prevention & response trainings for disability service providers and teachers. Call 781-388-4338 for information.

you can learn to do enough to give you time to flee or minimize harm to yourself.

In closing, let me paraphrase samples of my own writing from an IMPACT class:

A. I like the old "Avengers" television show of the 1960s, where the dapper leading actor had an umbrella that he could jauntily walk with, but then when he needed to, he could press into use the sword hidden within the umbrella. Wouldn't that be something if your assistive devices for daily living could also be weapons as necessary against nefarious people?

If you could lift your legs, which maybe you can't at the moment, but perhaps with adrenaline flowing you could do it briefly, you could smack an attacker with your braces. And if you wear braces on your arms and could swing your hands, you could leave an attacker wincing from the metal hitting their jaw.

I sound like I am writing a superhero cartoon, with caption bubbles saying 'bam, strike, hit to the groin'. But this is no cartoon, this is our lives, and we are giving ourselves options to survive. Use what you have.

B. I used to get around by bouncing on my rear as an infant. One day, I just stood up from my rear and started walking. So here I am decades later trying to do something similar, I am trying to coordinate movements once again. And, maybe like when I was an infant and moved around differently from those kids who crawled, I don't quite do self-defense the way others do it, or as smoothly as others do it. Someday I may have to rely on my new skills, and I will, as I did as an infant, stand up for myself.



IMPACT-Boston can be reached at 781-321-3900 or www.impactboston.com.

IMPACT's Self-Defense and Creative Writing Classes

were made possible by a grant from the Cambridge Arts Council and allows participants to attend at no cost to them.

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Disability Issues

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From the Editor

Dear Readers,

The recent #MeToo movement has generated a multitude of testimonies from people speaking out about their experiences of sexual assault or harassment. I've noticed that voices from people in the disability community have not been well represented in this movement. Yet, people with disabilities are vulnerable to being targets of violence and sexual abuse, perhaps even more so. Assaults are usually motivated by anger and/or someone's need to feel powerful. Therefore, abusers often seek victims they perceive to be vulnerable.

Sharing personal stories about violence, especially sexual violence, is extraordinarily difficult and each person has to make their own decision about when, how or if to share their story. As more people with disabilities are included in conversations about sexual harassment and abuse, it will make it easier for other people to come forward and find solidarity and support with others who are saying it happened to #MeToo. In this issue we bring you the article, *The PCA Who Raped Me* as a bold step toward telling one of these stories. If you have experienced trauma and/or abuse, please see the Information Brief on page 5 for classes that provide support for survivors.

Also in this issue, we offer our readers multiple articles and resources that provide information about how to defend yourself against many types of violence. Harassment happens to everyone, so knowing how to prevent and protect yourself against an attack is an important life skill for everyone. It's certainly essential for people with disabilities who need to be more creative and adaptive when it comes to defense strategies.

Marianne DiBlasi, Editor

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Love and Intimacy Corner



Bystander Intervention

by Ms. Love

ave you ever watched the news when they are reporting on a horrific incident and the reporter mentions people saw it happening, and they let it happen? Do you get upset about it and wonder why someone wouldn't jump into the fray to help a stranger, or even a friend? Some may say it is not their fight and they do not want to get involved. Others are afraid they will be in danger if they tried to intervene. But I say this, if your heart is in the right place, how can you not intervene? The real issue is, how can you think through what your intervention options are, and understand your level of safety and comfort with different approaches?

The Boston Area Rape Crisis Center (BARCC) offers bystander intervention trainings each year. I participated in one last year. The folks in attendance that day were equally divided between men and women. Adults of all ages came. People came as individuals or with someone. Most importantly, people came ready to actively participate in the training and discussion.

BARCC taught us that there are basically four intervention methods, and none is better than the other approaches. The intervention method you choose depends on the situation, your personal style, and your appraisal of your safety and the safety of the person about whom you are concerned. You might also use a combination of approaches.



The direct approach is when you call someone out on their behavior. It can be physical or verbal, but you should only do it if it can be done in a safe way.

The distract approach is when you interrupt the behavior of the perpetrator in some way.

The delegate approach is when you think someone other than yourself should intervene, so you tell a policeman, subway driver, etc. what's going on and ask them to intervene.

The delay approach is when you choose not to intervene in the moment, but you do it afterwards. For example, if you know the targeted person, you can follow-up with them afterwards to be sure they are okay. Or, if you know the perpetrator, you can follow-up with them afterwards and let them know what they did was not okay.

The highpoint of the training was when we broke up into groups. Each group was assigned one scenario to ponder and then act out in front of the rest of the training participants. This gave us time for in-depth small group discussion, as well as the chance to see many different scenarios and ways to intervene.

The group I was assigned to did not involve an issue with disability, so for you, dear readers, I wrote a scenario for you to contemplate and consider how you would intervene.

SCENARIO:

I was waiting for a bus, wearing an assistive device, a collar around my neck. There were many others also waiting, so I was not physically alone. And yet, I was physically alone when one of the men who was standing there came right up to me saying loudly that he could fix my neck; all he has to do is put his hands around my neck and pull.

I moved away from him, but he just followed me and came almost within touching distance, repeating that he can fix my neck by putting his hands around my neck and pulling.

Absolutely none of the many gathered people waiting for buses tried to intervene—either to keep him away from me, or to escort me away. I consider myself lucky that the bus I wanted came at that point. I was able to get on and escape the man who was threatening me.

Dear readers, how could you have intervened to help this person with a disability? For more practice on bystander intervention, consider attending a training on the subject at BARCC or at IMPACT-Boston.

According to article in the *New York Times*, "Most women encounter harassment from a stranger at some time in their life, and one in six of all American women will survive rape or attempted rape in their lives." Yet, according to attorney and advocate Stephanie Woodward, the statistics are more harsh for people with disabilities: "Women with disabilities are at least twice as likely to be victims of domestic violence and sexual assault than women without disabilities...Only 5% of reported crimes against people with disabilities were prosecuted, compared to 70% for serious crimes committed against people with no disabilities...Abuse has a more severe negative effect on the self-esteem of women with physical disabilities than those without disabilities..."

Given such statistics, who better than people with disabilities to stand up for women and men, with or without disabilities, who are being threatened, harassed, abused? Who better than people with disabilities, people who themselves are more likely to be assaulted or abused, to understand the threat and stand up against abuse?

The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at DI.LoveandIntimacy@gmail.com. Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.

¹Phoebe Lett, "Taylor Swift's Priceless Dollar," New York Times, August 16, 2017. www.nytimes.com/2017/08/16/opinion/taylor-swift-groping-assault.html.

² Stephanie Woodward, "#yesallwomen Includes Women with Disabilities," Ms. Wheelchair Florida, May 29, 2014. www.mwfl2014.blogspot.com/2014/05/vesallwomen-includes-women-with.html?m=1

The PCA Who Raped Me... - Continued from page 1

(The second floor bedrooms were of no use to me anyway.) I was surprised when B came by my office to apply for the position.

B, a member of the support staff, and I were acquaintances, belonging to the same lunchroom table clique who ate together most weekdays. It turned out B was facing some major dental expenses not covered by our company's insurance plan. So free rent and extra cash were both welcome prospects. My out-of-state family expressed reservations about the unorthodox opposite sex caregiving arrangement and living situation, but they were in no position to object. This wasn't what I had in mind either, but I was feeling desperate.

This was B's first time as PCA and my first time training a PCA, as well as first time having someone of the opposite gender help me with intimately personal things like toileting, bathing, and dressing. But we really got along well together, and somehow we muddled through, settled into a good daily routine, and conveniently shared the short commute to the office. At first, our lunch table group eyed us a little oddly, probably gossiping about us behind our backs. But that too returned to normality. The new caregiver and I actually became quite close, either because of, or in spite of the enforced intimacy. Everything was moving in the right direction, until yet another urinary tract infection struck, and I was rushed to the hospital in the middle of the night with a terrible fever.

After two days of IV therapy, I was told I could be discharged to home with twice daily self-administered inter-muscular shots of antibiotics. It was a great relief to arrive home in the afternoon. That night, after B had transferred me onto the bed, we prepared for the antibiotic injection. I wriggled out of my usual bedtime attire to give easier access to my thighs for the purpose. B swabbed my thigh with an alcohol wipe and gripped it to present a roll of flesh as target. She somewhat nervously

stabbed me with the syringe, eased the plunger back to check for blood, and completed the injection quickly. Something about the whole situation made me inadvertently, but obviously, sexually aroused.

Before I realized what was happening, B had stripped naked, climbed on the bed, and straddled me – no embrace, no caress, no foreplay, not a word. The sex act quickly concluded, B dismounted, kissed me on the cheek, gathered clothes from the floor, bid me goodnight, and headed upstairs to bed. I was left in a confused daze, head spinning, and couldn't get to sleep for hours. Everything had happened so quickly—the injection, the sex. I felt unfulfilled, but guilty about what physical pleasure I had experienced, wondering whether I had invited this by putting myself in a compromising position. Maybe I should have held out for a same sex caregiver, I kept thinking.

The next morning over breakfast neither of us spoke of what had transpired. Perhaps B was as embarrassed as I was. That night we reenacted the same scene, again mechanically, wordlessly. Once again caught by surprise, I realized I should have spoken up earlier, should have told B how used and unclean I felt that first night. I was now complicit by my very silence. It was as if my chance to object had passed and now there could be no end to the cycle. But it did end a week later when Becky (not her real name) quit her job at the company, packed up her things, and moved away.

My screening of candidates for a replacement PCA took on new meaning after these uninvited sexual encounters and the emotional turmoil they engendered in their aftermath. I had in essence become another person's sex slave. Sure, there was some purely physical pleasure, but nothing loving, tender, or even erotic in the purely mechanical act, repeated nightly for a short time at Becky's instigation. She apparently had, for a time, reveled in the reversal of the traditional gender power dynamic. Like the female victims of date rape, I had felt helpless and violated, betrayed and defenseless.

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Classes for Survivors of Trauma and Abuse

All **IMPACT-Boston** classes are taught with an awareness of the lasting effects of abuse and trauma. Survivors regularly participate in all our women's, men's, LGBTQ, and youth classes. Some survivors prefer IMPACT classes that are specifically designed for people who have experienced abuse. Survivor classes have a deeper focus on the ways in which abuse affects people's experiences of their bodies and their safety.

Introduction to IMPACT for Trauma Survivors

This 4-hour class is designed for survivors of trauma who are interested in taking an IMPACT class but are not sure which class best suits their needs.

Take Your Power

This class was designed specifically to address the long-term effects of abuse on intimate relationships and sexual health.

Assertiveness and Boundary Setting

Many survivors find that the ability to set and maintain boundaries greatly enhances their sense of safety. This course is an 8-hour all-verbal course that teaches students the skills for effective communication and negotiation in stressful situations.

Take Your Power For Female Survivors of Abuse and Trauma

This 12-week course was designed specifically to address the long-term effects of abuse on intimate relationships and sexual health.

For more information, visit www.impactboston.com/classes/classessurvivors/ or call 781-321-3900.



Intimacy and Trust

By Ray Glazier

or consumers like me whose PCA services necessarily involve toileting, bathing, and dressing, the unavoidable physical intimacy is fraught with complications. For one thing, it is difficult to argue with someone who has seen you naked, or correct someone's technique for wiping your backside. Yet we face these awkward situations all too often, indirect results of enforced physical intimacy that is usually equally uncomfortable for each party to the relationship.

Perhaps you have experienced the documented, unwelcome phenomenon of (temporarily) able-bodied persons confiding in you their otherwise unspoken inner feelings or secret thoughts. PCAs, or consumers as well, may try to paper-over awkward intimate situations by divulging irrelevant personal information. For example, while helping me bathe, one guy regaled me with intimate details of his wedding night with his ex. Another PCA recounted how her father had routinely forced her to give him oral sex when she was a girl. TMI!

In an article that ran in the *Disability Issues* Spring 2018 issue, Joan Burrows provided me with this telling postscript to her story about Walter: "The women from the [home health] agency had more or less complete control. They set the hours. And they smoked in his room. (This was a man with lung issues.) Walter was a normal, sexual man. Some women used this to further their control and even promised he could move in with them. I believe he gave them some money, to treat themselves to things."

In the PCA Corner column, I have previously discussed the importance of a degree of interpersonal distance in maintaining the employer-employee distinction in the consumer-PCA relationship. That said, I personally find this problematic in practice because:

- a) my PCAs are part of my household,
- b) my family resides in another state,
- c) my multiple disabilities (speech impairment in particular) isolate me from peers, even within the disability community,
- d) I have no significant other in my life at this time, and
- e) I am an introvert by nature.

So the bulk of my day-to-day social interaction is with my PCAs.

Trust is a key component in the consumer-PCA relationship. Because I can't reach to enter my debit card PIN at the ATM, my PCAs know the number sequence; I trust them with it (and daily monitor my bank account transactions on-line, just in case). Your PCA should be your trusted friend and ally, but probably not be your BFF. Any PCA is not forever; there will always be turnover and partings, sweet or otherwise.

The first step in a trust relationship with your PCA takes place in the initial job interview: Some seasoned consumers simply recommend 'trust your gut,' while one writer recommends 'trust your pet' on the theory that animals, especially dogs, are better initial judges of character than humans. Secondly, ramp up your trust gradually, step by step. A consumer friend leaves a \$10.00 bill on a table or on the floor, then waits to see if it disappears without a trace. I suppose this might border on entrapment, but she feels sufficiently trapped and vulnerable herself that she considers the test is warranted. Thirdly, as your new PCA begins to earn your trust, earn that person's trust by being a good, responsible employer:

- 1) Be considerate; do not set unreasonable expectations or make unreasonable demands.
- Be kind and polite, as you would to any other person; 'please' and 'thank you' enhance your dignity, not compromise it.
- 3) Ensure that each PCA is paid on time for each hour worked; for MassHealth PCA Program consumers still using time sheets, this means making certain they are correctly filled out, properly signed, and timely submitted.



Always remember that trust is a mutual proposition. Furthermore, both consumer and PCA are often equally stressed financially. And typically consumers are no more eager to recruit a new PCA than the PCA is to go out looking for a new job. So both tend to daintily step around minor everyday problem areas in what I have called the 'PCA Tango.' They are pretty much equal partners in the dance. But the one-sided physical intimacy

in the relationship has bearing on the power dynamic involved. It leaves the consumer at a certain disadvantage. Not that mutual showers are recommended, of course.

Raymond E. Glazier, Ph.D. has decades of professional experience studying PCA issues, as well as decades of personal experience as a consumer in the MassHealth PCA Program. He is a principal of disAbility Research Associates LLC and welcomes comments or questions at ray_glazier@post.harvard.edu.





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FCT provides multicultural, multilingual and intergenerational programs that offer inclusive opportunities in the arts for children of all abilities and their families. Along with inspirational journeys into the arts, FCT strengthens participants' access to a variety of community supports.

FCT encourages the full participation of children and their parents, siblings and caretakers, always maintaining sensitivity and respect for children of different abilities and from a variety of cultural backgrounds. With an emphasis on serving low-income families, FCT provides free workshops, cultural field trips and other community arts opportunities.

All workshops are taught by an experienced team of visual and performing teaching artists in an accessible setting in English, Spanish and American Sign Language. Many of the teaching artists are elders, are living with disabilities and reflect the diversity of the participants.

To learn about cultural programming throughout the year, visit FCT's website www.familiescreatingtogether.org, email: familiescreating@gmail.com, or call (617) 522-4832.