

# IN THE AUTISM WORLD, WHY ARE WE AFRAID OF SEX?

BY MICHAEL JOHN CARLEY

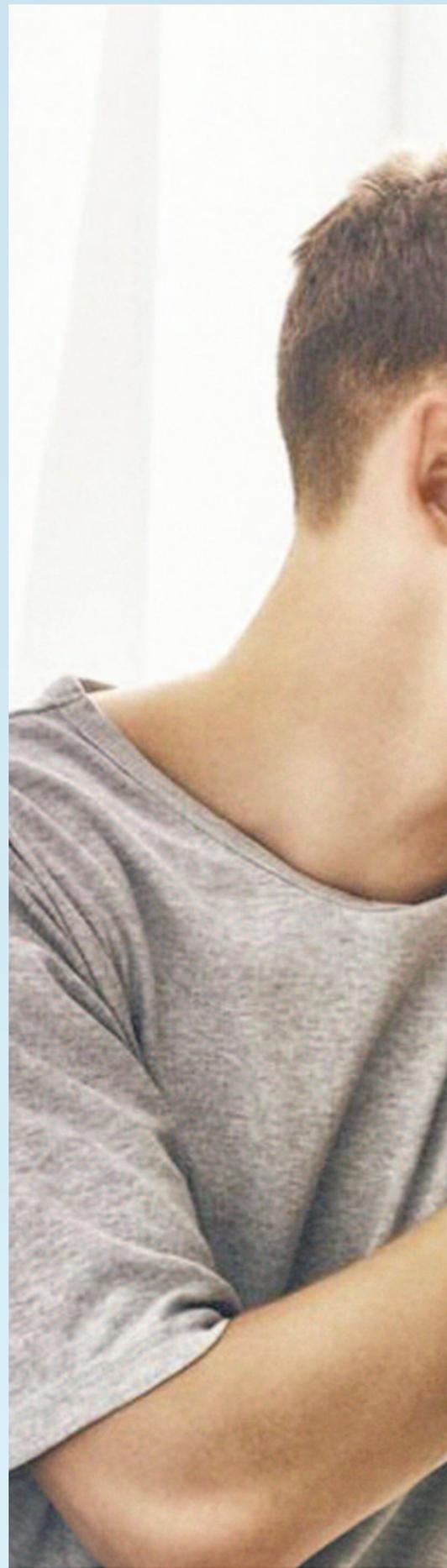
*[Editor's Note: This article is loosely adapted from a four part series Carley wrote for Sinkhole Literary Magazine. For access to the entire series, please contact the author through his website.]*

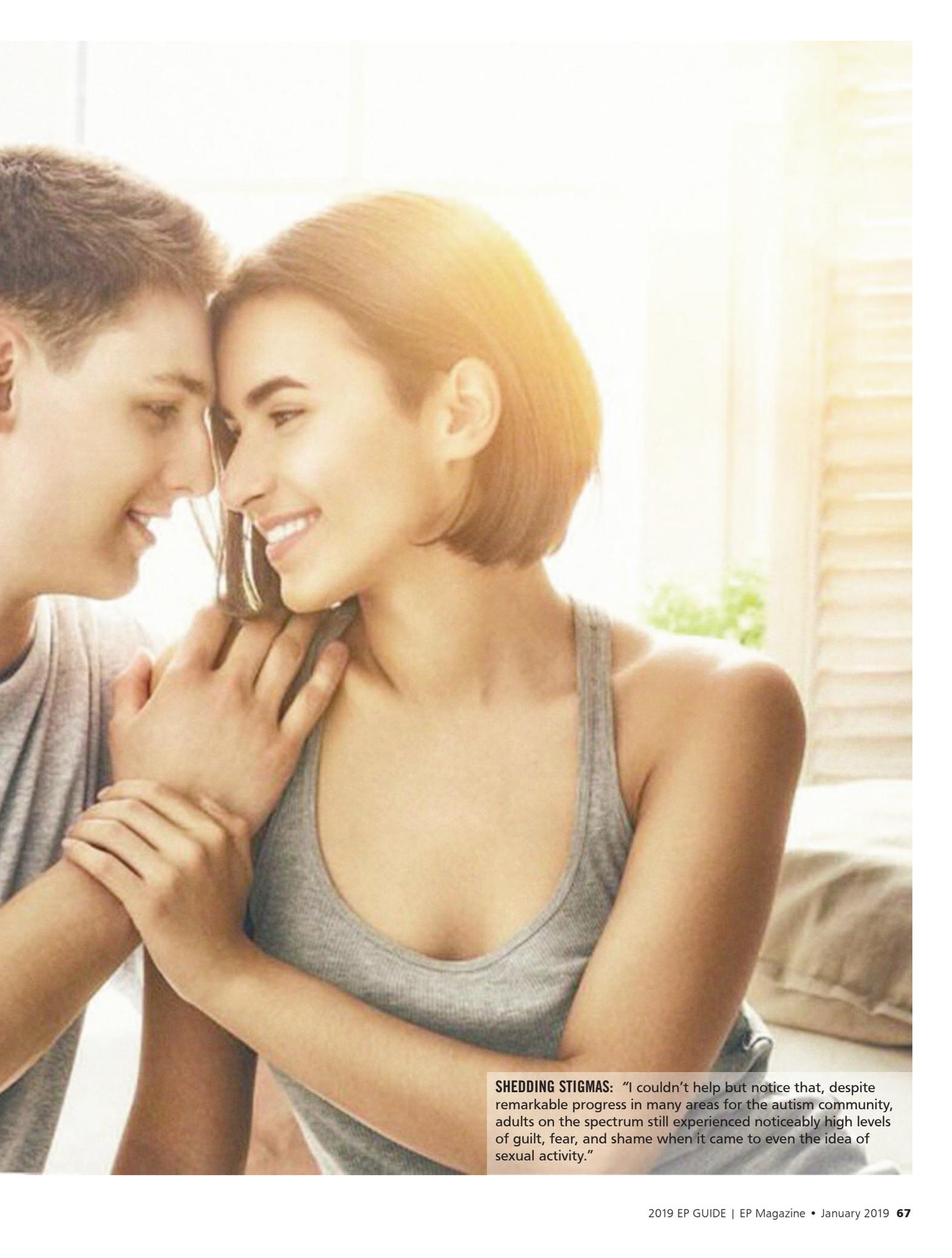
In 2003, I founded the Global and Regional Asperger Syndrome Partnership (GRASP), the largest membership organization in the world for adults on the autism spectrum. During my ten-year term as its first executive director, I couldn't help noticing that many members were terrified of sex. Despite remarkable progress in many areas for the autism community, adults on the spectrum still experienced noticeably high levels of guilt, fear, and shame when it came to even the idea of sexual activity. The rest of the world was starting to develop healthier attitudes about sex during this same decade, but almost none of that wonderful, reassuring, neurotypical world knowledge was reaching people with non-apparent disabilities.<sup>1</sup>

Additionally, many other spectrumites shied away from sex due either to rectifi-

able sensory issues and/or often-rectifiable social anxiety – yet I found no sensory or anxiety-reducing activities attempting to address their challenges. Entire sexual lives were being sacrificed because people were too embarrassed to ask for help, too lazy to provide the context needed to teach people about sex, or were secretly relieved that their children would be spared the “dangers” of a sexual existence. Even masturbation – “sex with one's self” – is an avoided topic. This cluster of forces continues to keep many of our folks unnecessarily celibate, even self-celibate.

This widespread, fear-based abstinence has appealed to our caregivers. Looking at all the available sexuality curriculums for individuals on the autism spectrum, the instruction experienced by most of our population (if we get any at all, as most of it is written for parents) is so overloaded<sup>2</sup>





**SHEDDING STIGMAS:** "I couldn't help but notice that, despite remarkable progress in many areas for the autism community, adults on the spectrum still experienced noticeably high levels of guilt, fear, and shame when it came to even the idea of sexual activity."

with relationship concerns, puberty instruction, or fear-based disclaimers regarding health and legal concerns... that it becomes impossible for us spectrum literal-thinkers to believe that sex is a good thing. As sex educator Al Vernacchio has made clear, we teach our kids (spectrum or not) that we do not want them to have great sex.<sup>3</sup> We want people to know how babies are made, how to avoid becoming victims of crime, and (if lucky) what will happen to our bodies at age 13 or so, but we seem morally opposed to training kids to (eventually) become confident lovers who experience fabulous orgasms.

That said, the scare tactics in our segregated universe have a legitimate, social origin.

## (Maybe) Why We're So Scared

Individuals with *all* disabilities have a medieval, awful, and trauma-filled history with sexual assault<sup>4</sup> in schools, institutions, on the streets as homeless adults, or in the supposed safety of family life; a terrifying legacy<sup>5</sup> that carries an infinitely higher degree of danger than what neurotypicals experience—especially for young women. Often, the abuse is hidden, and so the vast extent to which the problem exists goes mostly unacknowledged, even to this day.

In the early 1970s, a young journalist named Geraldo Rivera made his name by uncovering widespread mistreatment and neglect<sup>6</sup> at a then-respected New York institution for the developmentally disabled. The name of the institute, Willowbrook, has since become a word in our collective lexicon that resonates as a nightmare. But starting with the discovery of horrors like those at Willowbrook, society began examining other institutions (schools, even families), uncovering vast abuse in the process. We then set out to correct the problem,<sup>7</sup> and though the issue hasn't been eradicated,<sup>8</sup> we've made great strides.

Yet, as with so many other things, we jumped over the emotionally-healthy middle ground and landed in the opposite extreme.

Nowadays, too many authors and clinicians in the autism world regard themselves as “sexpositive” even as they conclude every sentence about how wonderful sex can be with a giant “BUT!” We are too afraid to admit without disclaimer that sex is not about horrors. We can't state the truth that, to most, sex is about pleasure.

My intention here is not to trivialize the dangers, like sexual assault, that sex educators warn us spectrumites about. Instead, I want the conversation to be framed differently. Bear with me...

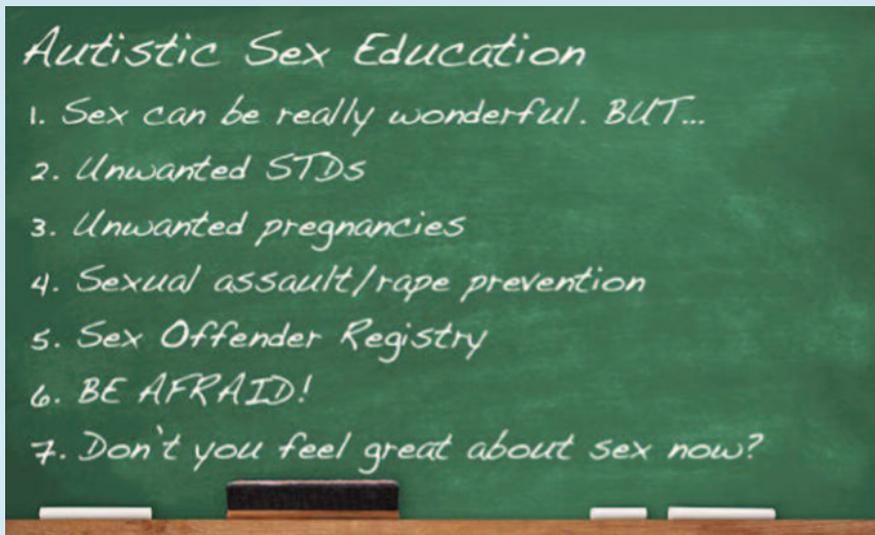
1. What if the imperative subjects of unwanted pregnancies, safe sex practices, and Sexually Transmitted Diseases (STDs) were categorized under the auspices of “Health” instead of “Sex”?
2. What if avoiding sexual assault, stalking charges, or the Sex Offender Registry, were listed under “The Law”? How would we spectrum-folk, as precision-based learners, regard the word “sexuality” then?
3. What if (for everyone) we stopped teaching sex within the context of developing relationships? I propose that this confuses us due to the infinitely more complicated subject of friendships and/or relationships—and nobody needs an existing relationship

*to become sexually aroused.*

There is so much potential happiness therein, and yet with the exception of death, nothing seems to scare our society more than sex. All because we have to frame the subject amidst the aforementioned horrors.

Another part of the problem is religious influence.<sup>9</sup> While the ethical examination of sexual behavior may appeal to many, alongside the promise (that most major religions subscribe to) that monogamy works for everyone, I believe religious scripture is the basis for much of our ridiculous attitudes towards women, and it is the basis for pretty much all of our bigotry towards the LGBTQ community.

Another part of the problem is that parents, even the supposed-



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ly “cool” ones, overestimate their value as teachers. While well-intended, and maybe a good starter course, parental instruction herein needs context in order to become a helpful part of their child's education. And that context is this: Every generation is convinced it reinvented sexuality (myself included, folks). The child's generation will define their sexual existence, not their parents'.

Because of our educators' terror on our behalf – that we not succumb to the aforementioned horror stories – we spectrum-folk are also not being given confirmation of how pleasurable sex can be, how healthy sex is for the physical body, how no one has low self-esteem when experiencing an orgasm, or how many options individuals really have (as opposed to the limited options we are informed of). Even the most non-verbal of us will know what turns us on and what doesn't – regardless of whether or not we'll ever have sex with another person. And if raised in a heterosexual environment, very often – whether the caregivers are bigots or not – the option (and subsequent permission) that you might be different is almost never presented to you. Others who are quite verbal are usually given the standard “you'll figure it out” cop-out when, of course, “figuring it out” is a known diagnostic challenge for us.

Everyone needs instruction – even in the basics. And in our society, we often don't get it.<sup>10</sup> Many schools out there know they should teach their more-challenged spectrum students what mas-

turbation is and when and where it's appropriate. But these schools won't go near the topic.<sup>11</sup> Today, in the one of the most prosperous nations on earth, we ruin lives in the name of the highly elusive concept of "safety." Helen Keller, of all people, teaches us that:

*Security is a superstition. It does not exist in nature.*

*Life is either a daring adventure, or nothing.*

Our instructors instead try to spin the seemingly mandatory, fear-based instruction as being simultaneously full of positive attitudes. But the result is a spectrum adult that is scared and confused, not positive. We need instruction that is healthy and positive,<sup>12</sup> clear and with context, and open to all possibilities.

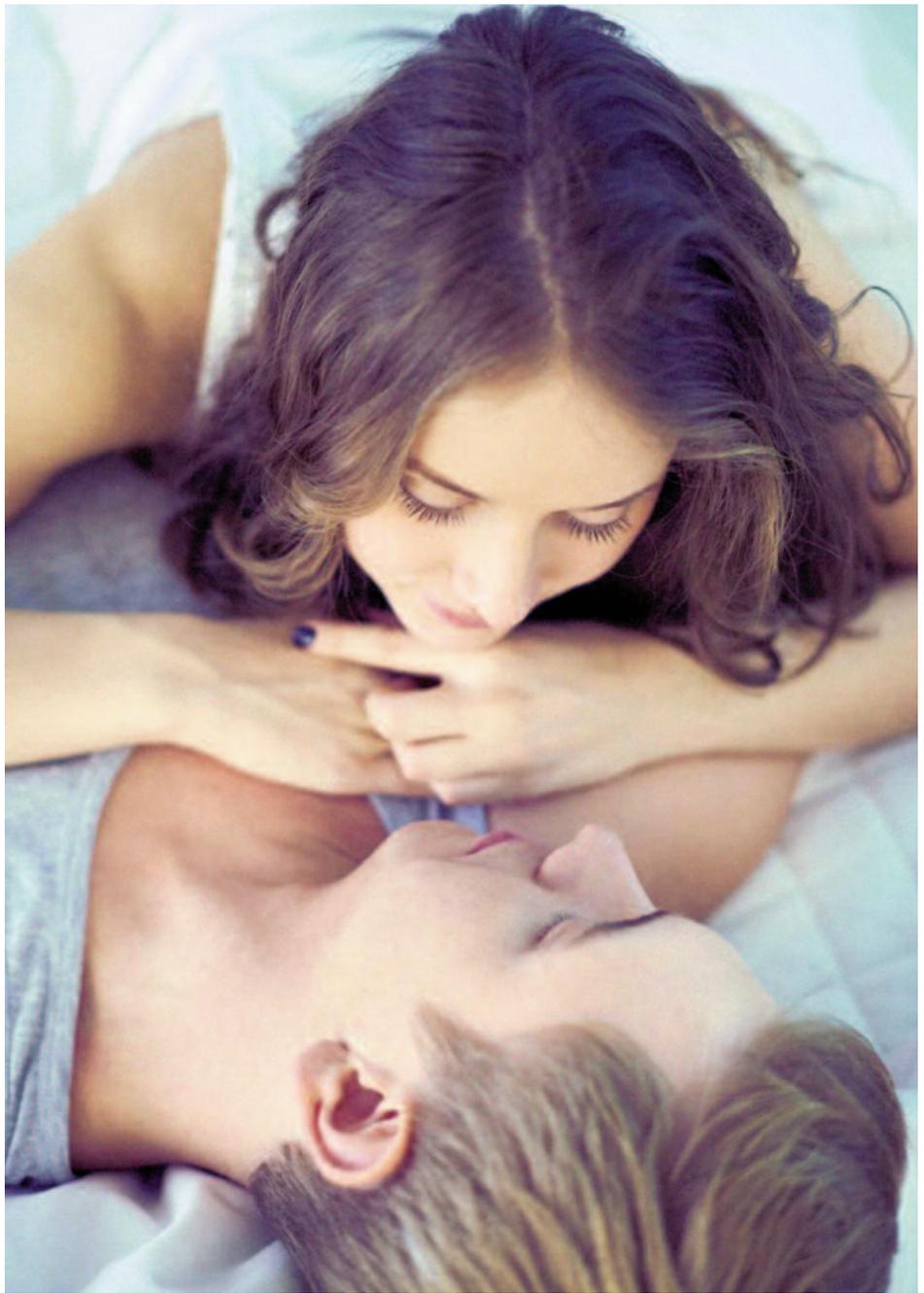
## Sex is Not "Complicated:" It's Awesome

Look, being people on the spectrum, we are not a population with the best chance of obtaining the great, mountain-moving, reciprocal love affair, nor do we have the same shot at career fame that neurotypicals have. Sex might be the best thing we have... if we're allowed, and if we allow ourselves. If reciprocal relationships are truly beyond us, then why not make masturbation a more important declaration of self-love?

I can't tell you how many times I've run into a clinical professional or a self-contained classroom teacher who's worked with significantly-challenged spectrumites, and who has a story about that non-verbal male who one day "whipped it out" and began masturbating in a supposedly-inappropriate setting. The clinicians all tell this first-person narrative the same way – by bravely admitting how freaked out they were about how to stop it.

*And yet no one tries to imagine what's going on in the mind of the spectrumite.* He's just discovered the greatest thing since sliced bread, and you're telling him it's wrong to do it?

Even today, some still think it is okay to bypass instruction on such challenged folk as to the changes their body will undergo during puberty. However, though our minds are different, our bodies usually grow at the same rate as everyone else. Neglecting such instruction may lead to future problems that are very hard to reverse; or as I like to say, "If you think



**BREAKING THROUGH:** "Our barriers to promoting healthy attitudes stem not from logic, but from unconscious, semi-conscious, or conscious moral objections – often-flawed value systems that have been embedded in us whether we wanted them or not."

*you've seen behavioral problems, and you don't tell them what's going to happen to their body during puberty? You ain't seen behavioral problems yet."*

Our barriers to promoting healthy attitudes stem not from logic, but from unconscious, semi-conscious, or conscious moral objections – often-flawed value systems that have been embedded in us whether we wanted them or not. And the analytical truth is that they have no place influencing what at root, is a discussion about biology.

## The Autism World is NOT "Sexpositive." Here's Why...

In 2004, one year into my tenure at GRASP, I got the first of what would become several similar phone calls. The mother of an adult spectrum male called to ask if I could refer her to any "disability-friendly escorts" for her Asperger son. She felt that her child, who reportedly had never encountered reciprocated sexual activity, needed the confidence of experience in order to develop and go forward as a sexual



**CLOSING THE GAP:** “While not sexpositive, the autism world isn’t “sexnegative.” It wants to move forward, and it does move forward, but at such a slow pace that the discrepancy is beyond noticeable and the knowledge gap grows steadily between us and the neurotypical world.”

being. The only alternative was to wait even more years (her son was already in his 30s) until he (hopefully) gained the social skills that might bring about that beautiful combination of attraction, confidence, and informed consent. She knew that banking on the latter combo, i.e. waiting *more* years, was a risky gamble, if not a sadly dubious assumption.

I wondered how I felt about this, and shared the conversation with my wife Kathryn. I shared how I felt as a fellow spectrumite, as an executive director, and simply as a person wondering how much cognitive groundwork was necessary in order for a somewhat-challenged person to process such an experience. I concluded not only that I had no right to judge him, or his mother, but also that if the sex worker (the justifiably/politically correct term for “escort/hooker/prostitute”) was the only experience he would ever have, that yes, I’ll say it...this was far better than no sex at all.

Kathryn’s conclusion was slightly different.

*“So, you’d throw away your career to become a pimp?”*

She was right, and I obeyed; but the quandary only intensified. As the epiphany of adult diagnosis continued to explode until 2010, I not only got more calls like these from parents, I also started receiving confidential communiques from adult film actors, and sex workers, who *themselves were getting diagnoses of Asperger’s syndrome*. From my standpoint, I had quite the elephant in the bathtub – as the clinical world grappled with spectrumites’ relationship to porn, the idea that the actors we watched were often us was really not on anyone’s radar but mine.

What to do with such knowledge? I sought advice from a few colleagues, trying to open this can of worms as gently as I could. But the autism world didn’t just say, “Maybe not now.” The autism world made it clear, *“Michael John, we love you. But on this one? Shut the \$#! up.”*

So while I continued to support these adults as I would any GRASP members, I did not write about the subject. Many of them wanted out of their professions. But equally vexing was that many others didn’t. They liked sex, and whether they wanted primary romantic partners or not, they were sure they stunk at relationships anyway – so why not? The diagnosis, as with all of us, felt like a positive validation for why they were who they were, and why their lives were as they were.

## The Sex Offender Registry

While the topic deserves more time than I will give herein, the sickening over-use of the Sex Offender Registry<sup>13</sup> (SOR), if not an overall Draconian criminal justice system,<sup>14</sup> has also been a very visible, “sex negative” influence on my years at GRASP. Too often, people with autism are railroaded into signing confessions (regarding many crimes) they did not have to sign, or did not understand, because their spectrum trauma only wanted the detective or District Attorney to stop yelling at them. Teenagers have had their lives ruined for consensual acts.<sup>15</sup> Other spectrum individuals, who had committed legitimately illegal offenses, such as downloading and viewing the wrong kind of porn<sup>16</sup> – including that which involved children – should have incurred lighter sentences with an educational component if the offenses were as non-violent as they often were. But no, in a scene that spoke so much about who Americans are as a people,<sup>17</sup> the powers that be insisted that they be allowed to destroy the lives of these young people forever<sup>18</sup> through hard time and the SOR. We are so sick that we cannot see anything wrong with sending someone away for years of hard time because they viewed the wrong kind of porn online...even though we know it means that they will be raped repeatedly once incarcerated.<sup>19</sup> One could argue that this counter-productive<sup>20</sup> era has inflicted a

collective trauma on all of us in the autism world, and not just on the individuals whose lives were destroyed. In our consciousness, the prevention of falling into the clutches of a corrupt, and Kafkaesque criminal justice system...easily supersedes healthy sexuality.

## The Autism Community Pretends to Move Forward...

Well, maybe that subtitle isn't entirely fair...While not sex-positive, the autism world isn't "sexnegative." It wants to move forward, and it does move forward, but at such a slow pace that the discrepancy is beyond noticeable and the knowledge gap grows steadily between us and the neurotypical world. As the new millennium dawned, non-spectrum communities were beginning to tune into Dan Savage and Esther Perel, yet we were still having issues with allowing moderately-impacted spectrumfolk to pursue sexual lives. And later, in the middle of the last decade, as porn and its performers were becoming legitimized in mainstream culture (or at least less and less stigmatized), the very existence of an LGBTQ influence on the spectrum was becoming acknowledged not through invitation, but through much kicking and screaming. Today, no one provides the context that watching porn needs – in order to avoid the minefields that porn presents to an uneducated viewer. Yet far too few of us provide an alternative, and so porn has become the de facto sex ed.<sup>21</sup>

Lastly, spectrumites these days are finally being encouraged to feel sexual, and to think of themselves as sexual beings. But this is still allowed in the context of the sexual void. Look at the speaking circuit: The spectrum sex speakers that we are comfortable promoting actually *haven't experienced much sex* – it's like the employment book written by the person who never held a job for much time (lots of "don't"s, but very few "do"s). We are showing our pain, sometimes bravely, and that moves folks. We cater to the neurotypical world's desire for warm and fuzzy wholesomeness, using words like "naughty;" the sexual zoo exhibit that allows for subliminal pity, therein pleasing and reassuring its audience, because God forbid any of us should realize that we deserve pleasure,<sup>22</sup> that there is nothing noble in rejecting it, that it is so easily accessible, and that it carries significant benefits to both our physical and mental well being.

## More Lies That People WITHOUT Autism Live By

The subject of sex is unique for the autism universe not because healthy sexuality is something we fail to successfully implement. It's unique because herein, the neurotypical world fails too. The large discrepancy between what we get to learn and what the neurotypical world gets to learn is the basis for this article. But the situation is remarkable because neurotypicals don't have it that good either—we're bad at teaching sex to everyone.

Despite our economic advantages as Americans, sex has always been a topic we've struggled with. While we may never reach the emotional health of the Dutch<sup>23</sup> (where it is no coincidence that an extremely low rate of teen pregnancy reflects programs providing free birth control, with no parental approval needed, to students 13 and older), or the French (attitude, attitude, attitude) on the subject of sex, we struggle far more than our relative privilege warrants. Herein, the struggles of people with disabilities are mere extensions of a larger, American problem.

Not to try to be too comedic, but part of our problem might have to do with having gotten off to a bad start. Four hundred years ago, remember, our first settlers had left a sexually-repressive England for the very reason that, for them...*it wasn't sexually repressive enough*. They were called "Puritans," who believed in Puritanism; a way of life that journalist, H. L. Mencken referred to as "The haunting fear that someone, somewhere, may be happy."

Thereafter we somewhat mirrored our European lookalikes, including up to the industrial revolution wherein the pressure for couples to marry<sup>24</sup> both emerged and gained the stronghold it still maintains today. However, fidelity (99% for men) back then was not a staple of the marriage contract. Males were allowed to roam freely so long as the heterosexuals did not encroach upon "good" women whose reputations often dictated whether they lived or died. LGBTQ folks made arrangements in dangerous secrecy, and straight women, unlike their straight male counterparts, faced social and financial ruin for sexual contact outside the marriage.

Later, starting in the post-World War I era, we first saw pressure for true monogamy amongst *both* heterosexual partners. It began as a backlash against widespread outbreaks of venereal disease, and after World War II became more of a cultural preference rather than strategic element of disease control. And after the pill's emergence in the 1960s, thus freeing sex from the fear of reproduction, pretty much all marginalized and unmarginalized groups began their real pushes down the path towards sexual transparency.

There've been thousands of contradictions along the way, some of which today act as elephants in the bathtub (if a spectrum person may be allowed a euphemism). For example, we argue incessantly about how sexual education should occur in the schools.<sup>25</sup> But doesn't our very (worthy) desire for a diversified society herein bite us on the rear end? When we accept people of differing faiths and cultures into public education, we are therein allowing the conservative factions of almost every major religion—most of whom preach against pre-marital sex (especially for women)—to thrive and spread their fear-based instruction in our schools. This is another reason why school classes reframed as "Health," "Violence Prevention," "What the Law Tells Us," or "Self-Esteem 101" might win more approval from (if not sneak by) the conservative crowd.

## A Book's Complicated Journey

When I left GRASP I did do something. I wrote a book called *The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!* But the book had a more complicated journey than I expected.

In 2014, I signed a two-book deal with one of the three autism trade publishing companies (hereafter referred to as "Publisher A"). One of the two books, the one I would write last, would be the "big, fat sex book" I'd been dying to write since early in my GRASP tenure. My commissioning editor was a young, LGBTQ woman, and she and I really saw eye-to-eye on what the book should look like. But halfway through the writing of the book, as the first book (on unemployment) came out successfully, she left for a job at another publishing house. So as I enjoyed the honeymoon period from the first book in my two-book deal, I also started to put the finishing touches on the sex book, including the soliciting of testimonial quotes from better brains than mine in the autism field. I got lucky. I got raves by authors like *Far From the Tree's* Andrew Solomon, and

*Uniquely Human's* Barry Prizant; clinicians and autism world luminaries like Sue Maren, Fred Volkmar, and Linda Walder Fiddle; and in the foreword, well-known disabilities and sex expert, Dr. Michelle Ballan, called my *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!* both “the most LGBTQ-friendly book of its kind,” and “Carley’s most passionate book yet.” Life was good!

Problem was... my cool, younger editor had been replaced. As soon as a draft of the sex book was seen in early 2016, Publisher A dropped the book within 36 hours. No “Hey Michael, can we talk?” Just an unceremonious email saying “We’re dropping you.” I’d known the owner for a decade, we hadn’t had any arguments, and we’d just published a highly successful unemployment book together, AND she had competed with Penguin for my very first book in 2006! When I initiated a conversation that asked “Are you kidding?”, they lied about context, and in a derogatory fashion utilized the words, “anything goes” to negatively describe my book.

But then, the owner of one of the other two autism trade companies, call them “Publisher B,” a main rival of Publisher A, called me up. “*Michael, your book has a found a home,*” and they quickly sent a contract. After I reviewed the contract, signed and send it back for their signature... crickets. Six weeks later, after many emails and follow up calls to “where are you?”, the owner of Publisher B called with his tail between his legs to tell me he couldn’t do it. He wouldn’t say why, but a spy told me that the authors of Publisher B’s old and existing sex books (for trade books rarely go out of print) had raised a large protest – How could Publisher B publish a book (mine) that so directly contradicted much of what they said in theirs?

What was so different about my book? Well, the views expressed in this article certainly ran counter to the prior literature. But my book also had several, very specific, “how-to” chapters (which, I will argue, we spectrumites are desperate for). These occupied most of the 72 sexually explicit illustrations. The characters drawn (by a wonderful Indonesian artist who had to keep his identity—both sexual and personal—anonymous) also included individuals of different skin colors, ages, and body types.

To be fair about the three autism trade companies (that I’m herein inferring as prudish) in the years 1998-2004, it was they that published all of the ground-breaking material that lifted autism literature out of the stone age. But since then, they’ve regurgitated the same info in book after book, and two of the three owners have since passed away. Nowadays, the ground-breaking books like *Far from the Tree*, *Uniquely Human*, *Neurotribes*, and *In a Different Key* all come from the mainstream publishing world.

Long story short, my book’s publication has merely been delayed, and has a happy ending forthcoming, but the point being is that the powers that be in the autism trade publishing world – being reflective of the greater autism world – are socially conservative, and not “sexpositive.”

## Conclusion

Our feelings are complex, yes, and the spectrum provides few absolutes for us to theoretically rely on. Whereas some of us require more closeness in a relationship, others require more distance and boundaries. But in other disabilities—physical disabilities—lie perhaps paradoxes that better test our assumptions.

What of the person who has no ability to control or utilize their hands, and yet their clitoris and penis work fine? In order to gain release by masturbating, they need help from another person. Are we so morally opposed as to object to someone, perhaps paid, who acts as their masturbator? What of the physically disabled couple who reside in an assisted-living or supportive housing facility, and who have decided they want to have sex together, yet they don’t have the physical means to join their genitalia? What if they need a third person to make it happen, to literally push the two bodies together? Are we to fire the orderly who facilitates this for them?

And what of the woman with massive mental health issues who has been deemed by the courts as too challenged to be able to provide informed consent? Is everyone she consensually sleeps with then subject to being arrested on charges of rape?

Luckily, we are not a culture that is *completely* bereft of critical thinking. While minors will always need to be protected from predatory grownups, movies like *The Diary of a Teenage Girl*, and *Call Me By My Name* (both admittedly, which are set in the era in which I came of age) challenge the inflexibility of modern times.

Finally, very few people (spectrum or no) are having too much sex. The vast majority of us are not having enough, and the opportunity for a magnificent, erotic life passes us by.

## ABOUT THE AUTHOR:

Michael John Carley is the Founder of GRASP, a school consultant, and the author of *Asperger’s From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum*, (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum...and Beyond!* and the column, “Autism Without Fear,” which for four years ran with the Huffington Post but is now at home with Sinkhole. Dozens of past “Autism Without Fear” columns can be found at <http://www.michaeljohncarley.com/index.php/articles.html>. And for more information on Michael John, or to subscribe to his updates, you can go to [www.michaeljohncarley.com](http://www.michaeljohncarley.com).

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