Inside this issue

Sexuality and sensory	
processing 5	
Parent2Parent 6–7	
Typical meds and the libido 8-9	
Inside Autism Delaware 10–	1



Our mission

To help people and families affected by autism spectrum disorder (ASD)





Human sexuality and ASD

is the vice president

training at Planned

Delaware's Sexuality

Education Training

of education &

Parenthood of

Institute.

How to explain sex and relationships

Human sexuality is part of every human being. It is part of us at birth and is with us until the day we pass on.

As parents, caregivers, and educators of individuals with autism spectrum disorder (ASD), many of us may be placed in the role

of sex educator or even relationship facilitator, but explaining sex and relationships to someone on the spectrum can feel very complicated. So, start simple: Explain the basics, and name the body parts using correct terminology instead of slang terms.

Start teaching when your child is very young. If your child is older, worry not. True, it's never too early to start, but it's never too late to start if you haven't already begun. Whenever you start, this will be the beginning of a lifetime of conversations.

Use the correct names for all the body parts. Don't skip silently past the child's private parts. If you don't know the correct names of the private parts, start learning them. Check out plannedparenthood.org, sexetc.org, or some of the books mentioned in this article or listed in the Resources box on page 4.

Continued on p. 3

Sun contributor Catherine Dukes, PhD,

Nearly every human being—including people with autism spectrum disorder (ASD)—craves romantic and sexual relationships. But "[h]istorically, individuals with disabilities have been denied rights to sexuality."1

Why? Fears and stereotypes often impede individuals with disabilities. Stereotypes include the belief that

people with ASD are childlike, nonsexual, over-sexual, unable to understand, unable to give consent, uninterested in sexual relationships, unable to develop or maintain a sexual or romantic relationship, or not able to get married or have children.

As a result, "[i]ndividual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has negatively affected people with IDD [intellectual and developmental disabilities] in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. People with [IDD] frequently lack access to appropriate sex education in schools and other settings. At the same time, some individuals may engage in sexual activity as a result of poor options, manipulation, loneliness or physical force rather than as an expression of their sexuality."^{2,3}

To move away from the fears and stereotypes and toward acceptance,

Continued on p. 4

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Ask for help; try to help others

In this issue of The Sun, you will find information that addresses a few aspects of human sexuality as well as some resources that may be helpful to individuals on the autism spectrum and their families. As in each issue of Autism Delaware's quarterly newsletter, the usefulness of the information and resources will depend on the individual's needs.

Admittedly, "human sexuality" can be a sensitive subject. The staff at Autism Delaware is willing and able to guide you through your concerns. Don't hesitate to give Autism Delaware a call. The phone numbers are listed in the box at left.

As president of Autism Delaware's board of directors, I am awed by the depth and breadth of programs and services that our organization provides to individuals on the spectrum and their families across the state. Our mission sounds simple: helping people and families affected by autism spectrum disorder (ASD). But accomplishing this goal means addressing the range of symptoms experienced by people on the spectrum as well as the range of traits that defines each individual. Because we at Autism Delaware want all individuals on the spectrum to live a purposeful life, our work is definitely cut out for us.

While Autism Delaware maintains an excellent professional staff, we are still a nonprofit. Each staff member is responsible for at least one organizational department and can be

swamped by the growing numbers and needs of the autism community. As a result, the lifeblood and essence of the organization rest on volunteers. Autism Delaware volunteers are a great help



Pete Bradley Board President

to the people who help families affected by ASD as well as to those families themselves. Volunteers are responsible for the smooth operation of extensive administrative efforts, advocacy, communications, programs, and fundraising. Their spectrum of assistance is crucial.

When your personal situation allows, please become an Autism Delaware volunteer. Share your unique talents, and help make a difference in our world and yours.

In turn, don't be afraid to ask for help when you need it. Sometimes, we hesitate to ask for help because we don't want to feel indebted or be an inconvenience to others, but this attitude will only isolate you.

Please know that the people you reach out to will feel personally fulfilled by the process. I've learned that this process can also be amazingly cathartic. So, my motto is now "Ask for help; try to help others."

Use it as your own motto if you like.

Pete Bradley

A service of Autism Delaware



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How to explain sex Continued from p. 1

If getting started with these terms feels awkward, practice saying them out loud when alone in your home or car. It's

How common is sexual abuse?

The Disability and Abuse Project 2012 National Survey on **Abuse of People with Disabilities** included about 7,300 individuals with disabilities, family members, caregivers, and responders to abuse.

Of the responders with any disability, 70 percent said they had been victims of abuse.

Of responders with a developmental disability (such as autism), 34 percent reported some type of sexual abuse.

In a separate 2012 study published in *The Lancet*, children with developmental disabilities and mental-health diagnoses were reported as 4.6 times more likely to be sexually abused than children without disabilities.

Sexual Abuse of Individuals with Developmental Disabilities, Brief One: Contributing Factors (Disability Rights Ohio, Columbus, 2015): 4.

important to use these terms without shame. Two critical reasons are sexual abuse prevention and being able to use common, medically correct terms when talking with doctors. Young people need to know that their private parts have names, that their private parts are theirs, that they can talk about their private parts, that they can ask about their private parts without being shamed, and that they have control over who touches their private parts.

As a bonus, parents might also tell their children with ASD how amazing their whole bodies are, including their genitals.

Let me get you started with a few basic terms:

- **Nipples**—Everyone's got them.
- **Vulva**—For girls or female-bodied individuals, the vulva is the external genitalia you can see between a girl's legs. The vulva includes the outer lips (labia majora), inner lips (labia minora), clitoris, urethral opening, and vaginal opening.
- A vagina is the "tube" from the vulva to the cervix and uterus. Calling all of a girl's external genitalia "her vagina" is like calling your entire face your throat.
- **Penis and scrotum**—For boys or male-bodied individuals, the penis is generally well-known. The scrotum is the sack under the penis that holds the testicles.

Teaching the real meaning of "private parts"

The developmental age of a child with ASD can differ greatly from his or her chronological age. Further, family values combined with developmental age can lead to great diversity around when and what is taught in the way of sex education. For toddlers and children, a critical message is "Your body belongs to you. Sometimes, parents and doctors may have to touch your private parts but only to help keep you clean or for medical reasons."

It's important to talk about "secret touching" or other terms that may signal sexual abuse. Tell your child that "a secret touch" is never okay, and he or she should tell a trusted adult if anyone engages in secret touching—and keep telling until someone intervenes.

Teaching sexuality and reproduction

In general, it is okay and makes sense to teach children what human sexuality and reproduction are. In fact, in 2008, The Arc and the American Association of Intellectual and Developmental Disabilities offered a critical and relevant source of information and policy-making ideas around human sexuality and people with intellectual and developmental disabilities (IDD), such as autism. For more about this paper,

see the article on page 1 entitled "Moving toward acceptance."

For teaching tools, I highly recommend these award-winning sex-education books by Robie H.

- It's Not the Stork (ages 4+)
- It's So Amazing (ages 7+)
- It's Perfectly Normal (ages 10+)

Hormones and masturbation

While masturbation is normal at any age in human beings, puberty brings an increase in hormones and sexual interest. Where the parents of neurotypical kids may think they can be hands-off in providing guidance around sex and relationships, the parents of teens with ASD need to supply extra

Note: Parents should review Harris's books thoroughly before sharing them with their children. Make sure you understand the content, and be prepared to share your values alongside the medically accurate information found in these books.

instruction and guidance. You may want to put your head in the sand, but don't! Comprehensive sex education is needed for many reasons. In addition to minimizing the risk of abuse, victimization, and perpetration, education can provide young people with understanding and skill-building around healthy relationships, consent, and social skills, which can enhance and benefit an individual's romantic life and sexual health.

This discussion may be difficult for you, so instead of scheduling time for "the talk," consider finding teachable moments. These moments can often be found during car rides, listening to music and lyrics, or watching TV shows. Parents can ask their children "What do you think about..." or other questions when sexual or romantic scenarios come up. These ongoing conversations can then open the door to sharing values, teaching medically accurate information, and dispelling common myths.

For more information, see the Resources box on page 4.





Moving toward acceptance Continued from p. 1



The Arc authored a joint position paper in 2008 with the American Association of Intellectual and Developmental Disabilities. The paper offered a critical and relevant source of information and policymaking ideas around human sexuality and people with [IDD], such as autism:

"Every person has the

right to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

"All people have the right within interpersonal relationships to

- develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose;
- dignity and respect; and
- privacy, confidentiality, and freedom of association.

"With respect to sexuality, individuals have a right to

• sexual expression and education, reflective of their

- own cultural, religious and moral values and of social responsibility;
- individualized education and information to encourage informed decision-making, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases; and
- protection from sexual harassment and from physical, sexual, and emotional abuse.

"With respect to sexuality, individuals have a responsibility to consider the values, rights, and feelings of others.

"With respect to the potential for having and raising children, individuals with intellectual or developmental disabilities have the right to

- education and information about having and raising children that is individualized to reflect each person's unique ability to understand;
- make their own decisions related to having and raising children with supports as necessary;
- make their own decisions related to using birth control methods within the context of their personal or religious beliefs;
- · have control over their own bodies; and
- be protected from sterilization solely because of their disability." 2,3
- ¹ Hartman, Davida. Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders (Jessica Kingsley Publishers, 2013): 16.
- http://www.thearc.org/who-we-are/position-statements/life-in-the-community/sexuality
- ³ aaidd.org (website for the American Association on Intellectual and Developmental Disabilities/News & Policy/Policy/Position Statements/Sexuality)

Planned Parenthood of Delaware's education department is now offering

- individual education and group sexuality & relationship education for people with disabilities.
- parent workshops, and
- professional trainings on sexuality and disability.

For a free education session, workshop, or professional training, call (302) 224-8099, ext. 5, or send an email to iweber@ppde.org.

Resources

- Planned Parenthood https://www.planned parenthood.org
- Planned Parenthood of Delaware https://www.plannedparenthood. org/Planned-parenthood-delaware Education Department (302) 224-8099, ext. 5
- Sex, Etc.
 (comprehensive sex-education information to improve teen sexual health)

https://sexetc.org

- WebMD
 - www.webmd.com/sex/features/ when-to-talk-to-your-child-aboutsex#1
- Boyfriends and Girlfriends:
 A Guide to Dating for People with Disabilities (2015),
 by Terri Couwenhoven
- Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders (2013), by Davida Hartman





Sexuality and sensory processing

Sun contributor Lauren Janusz, MOT, OTR/L, HPCS, is an occupational therapist with OPT Therapy Services in Delaware.

Sexuality shapes the way we think about ourselves and others. Sexual expression may occur in the context of an established healthy relationship or with one's own self. Healthy relationships are based on permission, privacy, protection, and pleasure.

People with autism spectrum disorder (ASD) are sexual beings. But what if sexual intimacy is uncomfortable? Sensory-processing issues are common in people with ASD, and these issues may affect sexual exploration and sexual expression.

"Sensory processing" refers to how your body receives information from your senses and how it responds to this information physically and emotionally. For example, a back massage may feel good to one person: He or she processes the massage and responds by relaxing. But another person may pull away from the massage: This individual processes the massage as irritating.

If you or your partner are sensitive to factors in the environment, remove them or control them for a more pleasurable experience. Some environmental factors to consider when exploring sexuality include (but are not limited to) the following:

- aromas
- air temperature
- body temperature
- body moisture
- ambient lighting
- colors or hues
- body exposure
- bedding
- background noise

Tactile defensiveness (also known as hypersensitivity to touch) may create a barrier to physical intimacy. To someone with tactile defensiveness, light touch may feel painful. An alternative may be deep pressure because this affects the proprioceptors (or sensors) in the muscles and joints. These sensors provide information about body awareness, which facilitates organi-



zation of the body's sensory systems. If applying deep pressure is pleasing to you or your partner, it may be beneficial to use initially and during sexual intimacy.

Vibration is another way to access the proprioceptors. Vibrators come in a variety of shapes and sizes, and many come with adjustable speed. Try vibration on your hands or shoulders before exploring other areas of your body to make sure the feeling is acceptable and desirable for you or for your partner.

Mapping erogenous zones is another way to explore sexual intimacy. An erogenous zone is an area of the body that has heightened sensitivity and may be any area of the body, not only genitalia. If one area of the body is uncomfortably sensitive to touch, another area may be more receptive to intimate touch. Stimulation of an erogenous zone may generate a sexual response.

Within all consensual relationships, open communication, time, and patience are key to developing healthy sexual expression. If you or your partner feel that sensory processing affects your sexual expression negatively, you may benefit from treatment or a consultation with a sex-positive occupational therapist.

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MacRae, Nancy, MS, OTR/L, FAOTA. Fact sheet: Sexuality and the Role of Occupational Therapy (2013). The American Occupational Therapy Association, Inc., Bethesda MD (https://www.aota.org/About-Occupational-Therapy/Professionals/RDP/Sexuality.aspx).

Want information about occupational therapists in your area?

Call Autism Delaware:

In northern Delaware, dial (302) 224-6020, and ask to speak to the resource coordinator. In southern Delaware, dial (302) 644-3410, and ask for the family service coordinator.







PARENT PARENT Written by parents for parents

Talk to your child early and often about human sexuality

Nobody wakes up excited to talk to their kids about private parts, reproduction, and sexual abuse. But unless you want them learning about their changing bodies and emerging sexuality from a misinformed classmate or a sitcom, start talking to your kids early—and keep talking to them!

Prepare yourself by consulting with your partner or spouse about how to approach the topic and arming yourself with some books and advice from professionals.

(For the record, I am not a professional. And just so you know: You are not alone; this topic terrifies me, too. Especially because my kid has autism and had a very limited vocabulary until he was about five years old.)

So you know why talking early and often is important, here's a terrifying statistic that came out of a 2000 study: Children with disabilities are 3.14 times more likely to be sexually abused than children without disabilities (Sullivan, P. M., and Knutson, J. F. "Maltreatment and disabilities: A population-based epidemiological study." Child Abuse & Neglect, 24(10): 1257–1273).

Scary statistics like this prompted me to talk to my son about his body because I knew he was more vulnerable to sexual abuse. I needed him to be able to tell good touches from bad touches, and he needed to know he could talk to me without feeling shame.

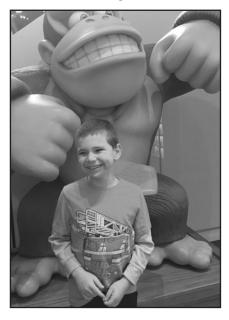
Most professionals say the information you share with your children should be honest, factual (using real names for body parts), and age appropriate. Of course, the answer to the

Cory recommends A Teaching Tale: My Body Belongs to Me (for ages 2-6), which is available from the Channing Bete Company at www. channing-bete.com.

question "Where do babies come from" will be different for a five year old than for a 15 year old. Having a child with an intellectual disability like autism makes the timing for these discussions even harder, since a child with autism could be 12 years old but have the comprehension skills of a 6 year old.

Most experts agree that you shouldn't wait for your kid to ask a guestion, because some kids may never bring it up, or they may interpret your silence to mean the subject is taboo.

Even though my kid is only eight years old now, my husband and I have started talking to him. We tell him that body parts covered by bathing suits should be kept private, and it's not polite to play with or explore your private parts around other people. When my son gets out of the tub with



Casey Gilden

a little erection, we explain that sometimes his penis is big and sometimes it's small. And when he thinks it's hilarious to make his butt "talk and dance," we remind him that it's not polite to shake his private parts at people.

Just because we've talked to our son a few times while he's young doesn't mean our work is done. I know it's important to talk often with kids about their bodies, human sexuality, and sex abuse because our children are constantly growing and changing. And they are able to understand more.

Kids become adults, and we know the guestions and changes are coming. It's better to be prepared than leave the subject to their own imaginations. Luckily, there are a ton of books and internet resources out there to help parents get through the uncomfortable moments. With a little research on your part, you'll feel more confident when talking to your child with autism about human sexuality.

—Cory Gilden

Symbols designed to help your child speak up

Designed for use only with Boardmaker Studio software, PCS Classic: Communicating About Sexuality, by Mayer-Johnson, LLC, offers 408 symbols to expand the expression of sexuality.

For more information, visit http://www.spectronics.com.au/ product/pcs-classic-communicating-about-sexuality-studioedition.

srcp.org

The online site Sexuality Resource Center for Parents includes tools, tips, and tricks for teaching children about human sexuality.







Written by parents for parents

PARENT PARENT

Growing into a sexual being

My son, Jake, who lives with autism, is almost 19 years old. When he reached a certain age, I was on the lookout for signs of puberty. Not knowing when he'd actually develop, I started to prepare him for what was to come:

"You are going to grow hair on your body," I said and then gave some specifics.

"No," Jake replied.

"One day," I continued determinedly, "you will shave your face like Daddy does."

"No," Jake asserted.

I ended up taking Jake to the same pediatric urologist who saw him as a newborn. The doctor assured me and my husband that puberty was, indeed, on the way.

As with all new processes for Jake, the beginning involves lots of protest; then, the protest fades as he gets comfortable with the new process. Fast forward a couple of years, and Jake notices the new hair growth I warned him about. He did not seem surprised or angered—only matter of fact. Luckily, leg hair grows slowly, so Jake had time to recognize that it was there to stay.

Jake has since graduated to partial face shaving with his Dad. My husband started the process by shaving in front of Jake and encouraging him to try. The teaching has been working well, but Jake has trouble holding the razor at the correct angle. There are many razors on the market, so if we need to make a change, we will.

Deodorant use was introduced to Jake as puberty began. To remind him, I used a CD-ROM with PECS [picture exchange communication system] from Pyramid in Newark. Jake's underarm hair serves as a target for where to rub the deodorant, and he likes a verbal prompt. The picture has been added to the list of things for him to do each day. Now, the PECs pictures serve as a reminder for Jake: If it's on the schedule, he has to do it. (No stinky teenage boy here!)

For parents, the most difficult part of their children's puberty is the sexuality aspect: How much do you tell them? And how do vou tell them?

Describing the mechanics of sex needs tailoring to each individual's level of understanding. What a child can handle today will be different next year, so keep the conversation going.

With Jake, I have never been certain that he would understand the "sex talk." I don't expect that Jake will ever be in a typical relationship, but he needs to be



aware so that no one can take advantage of him.

For help, I recommend reaching out to other parents going through the same stage or those whose children are a little ahead. The insight and knowledge will be invaluable as you navigate with your child through puberty.

I've noticed that, as my son was developing, I got used to the slow progress. As a parent, this slowness was a comfort and made me forget that puberty was coming, no matter what age Jake may be developmentally.

Recently, I talked to parents who have kids with special needs about how they approached the topic of masturbation. Although the act is natural, some teens need guidance. In fact, some boys have behavioral outbursts that can be aided by learning how to masturbate. With direction from your child's doctor or other professional in his life, you can get the information you need.

One family I spoke to had a security camera in the son's room from the time he was small because of the severity of his seizures. With the other monitor in the kitchen, it soon became common practice to turn the monitor off when the boy needed privacy.

This conversation brought up the idea of teaching the appropriate location for masturbation: Do you limit it to the bedroom? Or do you encourage using the bathroom? The more experienced parents shot down the bathroom. Why? Because our guys use public bathrooms in the community. If one bathroom is an acceptable place to masturbate, then any bathroom would seem appropriate. To avoid any unintended displays, these parents advised the use of the bedroom. This reasoning makes sense to me, but every family has to find what works for them.

Wishing us all good luck with each and every situation!

—Jen Nardo

Jen recommends these books written by Kate E. Reynolds:

- What's Happening to Tom? A book about puberty for boys and young men with autism and related conditions (Sexuality and Safety with Tom and Ellie) (First edition). Illustrated by Jonathon Powell.
- What's Happening to Ellie? A book about puberty for girls and young women with autism and related conditions (Sexuality and Safety with Tom and Ellie) (First edition). Illustrated by Jonathon Powell.
- Sexuality and Severe Autism: A Practical Guide for Parents, Caregivers and Health Educators. Jessica Kingsley Publishers (2014).

Typical meds taken by people with autism and how they affect the libido

"First named by Sigmund Freud, the libido is... an individual's general life energy. The libido was initially thought to be purely sexual energy however this understanding was broadened to include expressions of love, pleasure, and selfpreservation [sic]" (http:// psychologydictionary.org/libido).

People with autism spectrum disorder (ASD) are sometimes prescribed medications to help with a range of coexisting conditions. However, "[m]any medications can be a cause of decreased or loss of libido," notes Pharmacy Times (a fullservice pharmacy media resource). "Loss of libido is inherently connected with all other aspects of sexual



dysfunction, although it cannot be assumed that all medications that list sexual dysfunction as an adverse effect include specifically loss of libido. Patients can have orgasm dysfunction (anorgasmia) or erectile dysfunction without loss of libido, and some medications can affect just libido, just erectile function, or just orgasm function, whereas others can affect any combination" (http://www.pharmacytimes.com/publications/issue/2010/june2010/lossoflibido-0610).

The following medications, typically taken by people with ASD, were listed in Child-Autism-Parent-Cafe.Com (www.child-autism-parent-cafe.com/autism-medication.html) and Drugs.com (https:// www.drugs.com/condition/autism.html). Each med listed here and on page 9 includes the brand name (and the generic name). Not all side effects are noted—only those that may affect an individual's sexual function. This information is courtesy of Drugs.com.

Adderall (amphetamine/dextroamphetamine)

Major side effect-incidence not known: large, hive-like swelling on the sex organs or other areas

Minor side effects-incidence not known: decreased interest in sexual intercourse; inability to have or keep an erection; loss in sexual ability, desire, drive, or performance

Anafranil (clomipramine)

Common side effect: ejaculatory disorder

Less common major side effects: breast enlargement;

pain during sexual intercourse

More common minor side effects: change in interest in sexual intercourse; inability to have or keep an erection; increased interest in sexual intercourse

Less common minor side effects: absent, missed, or irregular menstrual periods; breast pain

Bumex (bumetanide)

Rare minor side effects: decreased interest in sexual intercourse; inability to have or keep an erection; loss in sexual ability, desire, drive, or performance; nipple tenderness; shorter than usual time to ejaculation of semen

Clozaril (clozapine)

Rare major side effect: decreased sexual ability

Less common minor side effect: change or problem with discharge of semen

Minor side effect-incidence not known: painful or prolonged erection of the penis

Dexedrine (dextroamphetamine)

Minor side effects-incidence not known: decreased interest in sexual intercourse; inability to have or keep an erection; loss in sexual ability, desire, drive, or performance

Effexor (venlafaxine hydrochloride)

Rare major side effect: menstrual changes

Effexor (venlafaxine hydrochloride) continued

More common minor side effect: decrease in sexual desire or ability

Geodon (ziprasidone hydrochloride)

Rare major side effect: persistent, painful erection

Haldol (haloperidol lactate)

More common minor side effects: changes in menstrual period; swelling or pain in the breasts (in females); unusual secretion of milk

Less common minor side effect: decreased sexual ability

Luvox (fluvoxamine maleate)

Rare major side effects: menstrual changes; unusual secretion of milk (in females)

More common minor side effect: change in sexual

performance or desire

Namenda (memantine hydrochloride)

Minor side effects-incidence not known: decreased interest in sexual intercourse; inability to have or keep an erection; loss in sexual ability, desire, drive, or performance

Paxil (paroxetine hydrochloride)

Common side effects: ejaculatory disorder; erectile dysfunction; male genital disease; decreased libido; delayed ejaculation

Other side effects: female genital tract disease; impotence; orgasm disturbance

Major side effects-incidence not known: painful or prolonged erection of the penis; swelling of the breasts; unexpected or excess milk flow from the breasts

More common minor side effects: decreased sexual ability or desire; sexual problems, especially ejaculatory disturbances **Less common minor side effects:** itching of the vagina or genital area; menstrual changes; pain during sexual





ead the packaging that comes with a medication's prescription. Look for the possible side effects so you can look for the possible changes in your child. The following terms refer to the severity of a possible side effect:

Major side effect—Talk to your doctor immediately.

Minor side effect—The side effect may disappear as the body gets used to the medication, but check with your healthcare professional if the side effect continues or if you are concerned.

Incidence not known—This term means the side effect was acknowledged but not counted. "These are usually the ones where a few people have reported it, but nothing was found in controlled studies" (https://www.drugs.com/answers/meaning-incidence-877250.html).

Paxil (paroxetine hydrochloride) continued

intercourse; thick, white vaginal discharge with no odor or a mild odor

Prozac (fluoxetine hydrochloride)

Common side effect: decreased libido

Major side effect-incidence not known: large, hive-like swelling on the sex organs or other areas

Less common minor side effects: breast enlargement or

pain; menstrual pain; unusual secretion of milk (in females) Minor side effects-incidence not known: painful or prolonged erections of the penis; swelling of the breasts or breast soreness in both females and males; unusual milk production

Risperdal (risperidone)

Rare major side effect: prolonged, painful, inappropriate erection of the penis

Less common minor side effects: absent, missed, or irregular menstrual periods; breast swelling or soreness; decreased interest in sexual intercourse; inability to have or keep an erection; loss in sexual ability, desire, drive, or performance; stopping of menstrual bleeding; unusual breast milk production

Serzone (nefazodone hydrochloride)

Less common moderate side effects: itching of the vagina or genital area; pain during sexual intercourse; thick, white vaginal discharge with no odor or a mild odor

Rare moderate side effects: change in sexual desire or performance; menstrual changes; pelvic pain; prolonged, painful, inappropriate penile erection

Moderate side effect-incidence not known: large, hivelike swelling on the sex organs or other areas

Less common minor side effect: breast pain

Minor side effects-incidence not known: unexpected or excess milk flow from breasts; swelling of the breasts or breast soreness in males

Silenor (doxepin hydrochloride)

Minor side effects-incidence not known: decreased interest in sexual intercourse; enlargement of the breasts; inability to have or keep an erection; increase in sexual ability, desire, drive, or performance; increased interest in sexual intercourse; loss in sexual ability, desire, drive, or performance; swelling of the breasts or breast soreness in both females and males; swelling of the testicles; unexpected

Silenor (doxepin hydrochloride) continued

or excess milk flow from breasts

Strattera (atomoxetine hydrochloride)

Side effects: dysmenorrhea (painful menstruation); erectile dysfunction; ejaculatory disorder; ejaculation failure

Less common major side effect: large, hive-like swelling on the sex organs or other areas

Rare major side effect: painful, prolonged erection of the penis

Major side effect–incidence not known: pelvic pain in males

More common minor side effects: bleeding between periods; change in amount of bleeding, in pattern of monthly periods; decreased interest in sexual intercourse; inability to have or keep an erection; loss in sexual ability, desire, drive, or performance; unusual stopping of menstrual bleeding **Less common minor side effects:** abnormal orgasm;

change or problem with discharge of semen; groin pain; swollen, tender prostate

Tofranil (imipramine hydrochloride)

Minor side effects-incidence not known: decreased interest or ability in sexual intercourse; enlargement of the breast; increase in sexual ability, desire, drive, or performance; swelling of the testicles; swelling of the breasts or breast soreness in both females and males; unexpected or excess milk flow from the breasts

Zoloft (sertraline hydrochloride)

Common side effects: decreased libido; delayed ejaculation; ejaculation failure

More common major side effects: decreased sexual desire or ability; failure to discharge semen (in men)

Less common or rare major side effects: breast tenderness or enlargement; unusual secretion of milk (in females)

Major side effect–incidence not known: large, hive-like swelling on the sex organs or other areas

Minor side effects-incidence not known: swelling of the breasts (in women); unusual secretion of milk (in women)

Zyprexa (olanzapine)

Less common major side effects: itching of the vagina or genital area; pain during sexual intercourse; thick, white vaginal discharge with no odor or a mild odor

Less common minor side effect: heavy menstrual bleeding





INSIDE Autism Delaware

Family support expanded



Autism Delaware has recently expanded its programming options for Delaware families affected by autism spectrum disorder (ASD) thanks to state funding through the Delaware Network for Excellence in Autism (DNEA). Established by the Delaware legislature in 2016, the DNEA is a multi-agency collaborative network led by the University of Delaware's Center for Disabilities Studies. The goal is to increase the available training surrounding ASD.

Autism Delaware's expanded family support services are organized around the theme "Reach out before you burn out." The program provides

a year-long calendar of available parent training and accessibility through Facebook Live, plus a new collaboration with the First State's education program, the Delaware Autism Program (DAP). Called Autism 101, it addresses a range of needs noticed over the years by DAP and Autism Delaware staff.

"Through this program," explains Autism Delaware family support program manager Annalisa Ekbladh, "we can train families with children who are newly diagnosed with ASD. By 'training,' we mean help in understanding what autism is, working with your child who has ASD, and finding resources in the community as well as other important components."

The calendar of available parent training includes professional speakers with backgrounds specific to ASD issues. "The workshops take place in Autism Delaware's Newark and Lewes offices," notes Ekbladh, "and air simultaneously on Facebook Live so that busy parents and caregivers have easy accessibility to the information.

"Our workshops on Facebook Live have been incredibly successful so far," adds Ekbladh. "Because Facebook Live is so much more interactive than webinars, families can ask questions and get answers in real time. The workshops only began in April, and the first one was viewed 943 times. And the second was viewed 1,300 times in the first two days!

"An unintended benefit of this format," continues Ekbladh, "is the parent connections that have been created. In this format, parents readily share their experiences and support each other, all in real time."

Also with the state funding through the DNEA, two new family navigators are being added to the Autism Delaware staff. Both navigators are bilingual, so their goal is to provide more outreach to Delaware's Spanish-speaking community as well as greater access to families affected by ASD.

Finally, DNEA funding provided the mechanism for a collaborative effort with autism agencies, such as Autism Delaware, DAP, Nemours/Alfred I. duPont Hospital for Children, La Red Health Center, the University of Delaware's Center for Disabilities Studies, and Delaware Family Voices. The goal is to create a stronger community by addressing any overlap and gaps in supports and services. "We all see families in difficult contexts," says Ekbladh. "By collaborating with each other, we can develop a conduit to help all families in need."

For more information, visit autismdelaware.org. Or call Annalisa Ekbladh at (302) 224-6020, ext. 218, or email her at annalisa.ekbladh@delautism.org.

Walking the walk

Almost 3,000 people "walked the walk" for autism this year by helping to fundraise for Autism Delaware's critically needed supports and



services. The first leg of the statewide event was April 1 in Cape Henlopen State Park; the second, April 8 in Fox Point State Park.

In addition to personal fundraising, generous donations from businesses across Delaware also contributed to the effort. Autism Delaware gratefully acknowledges champion walk sponsors Swift Pools as well as partner sponsors Hertrich Toyota, Highmark Blue Cross Blue Shield, the Freeh Group, Bath Fitter, the Wawa Foundation, and Tybout, Redfearn, and Pell.

Altogether, more than \$180,000 was raised. "Fundraising events, such as the Walk for Autism, help provide the income needed to make critical programs a reality and bring our community together," says Autism Delaware executive director Teresa Avery. "We offer family support, clinical services, adult employment, advocacy, and awareness. There's a growing need across the state—and we need to meet it!"

To the 140 volunteers who worked the Walk for Autism in Lewes or Wilmington:

You ensured that more of the raised funds can go where they're needed.











July-September 2017

Autism Delaware programs

July

1—Sensory friendly movie: *Despicable Me 3.* Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

5, 12, 19, 26—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00PM. Register: Karen. Tuohy@red clay.k12.de.us.

13

—Grandparents support group. Autism Delaware Lewes office. 9:00–10:00AM. R.S.V.P.: Dafne Carnright or Gail Hecky at (302) 644-3410.

—Bounce night. Hopping Good Times. 23 Cochran Dr. Camden. 5:30-7:30PM. R.S. V.P.: Gail Hecky at (302) 644-3410.

-Sensory friendly movie: TBD. Westown Movies. 150 Commerce Dr. Middletown, 10:00AM.

—Night at the Blue Rocks. Frawley Stadium. Wilmington. Picnic at 6:15–8:15PM. Game at 7:05PM. Register: Kris Grant at (302) 224-6020.

22—Sensory friendly movie: Ferdinand. Carmike Cinemas in the Dover Mall. 1365 North Dupont Hwy. 10:00AM.

August

2—Parent coffee hour. Hampton Inn. Middletown. 9:30AM. R.S.V.P.: Jennifer Sparks at sparkjm@aol.com.

2, 9, 16, 23, 30—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30-7:00PM. Register: Karen.Tuohy@redclay.k12. de.us.

—Grandparents support group. Autism Delaware Lewes office. 9:00-10:00AM. *R.S.V.P.:* Dafne Carnright or Gail Hecky at (302) 644-3410. —Bounce night. Hopping Good Times. 23 Cochran Dr. Camden. 5:30–7:30PM. *R.S.V.P.*: Gail Hecky at (302) 644-3410.

19—Sensory friendly movie:

August continued

TBD. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.

20—Beach picnic. Cape Henlopen State Park. Pavilion 1. Lewes. 10:00-2:00PM. Register: Gail Hecky at (302) 644-3410.

21—Grandparents support group. Autism Delaware Newark office. 6:30-7:30PM. R.S.V.P.: Heidi Mizell at (302) 224-6020.

For an upto-date list of Autism **Delaware** programs, visit autism delaware. org.

September

6, 13, 20, 27—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30-7:00PM. Register: Karen.Tuohy@redclay.k12.de.us.

9—Sensory friendly roller skating. Christiana Skating Center. 5:15-7:15PM.

12, 19, 26—Lego. Autism Delaware Newark office. 6:00-6:45PM and 7:00–8:00PM. *Register:* Heidi Mizell at (302)

13—Parent coffee hour. Panera Bread. Wilmington. 7:00PM. Register: Heidi Mizell at (302) 224-6020.

—Grandparents support group. Autism Delaware Lewes

office. 9:00-10:00AM. R.S.V.P.: Dafne Carnright or Gail Hecky at (302) 644-

—Bounce night. Hopping Good Times. 23 Cochran Dr. Camden. 5:30-7:30PM. *R.S.V.P.*: Gail Hecky at (302) 644-3410.

16—Sensory friendly movie: TBD. Westown Movies. 150 Commerce Dr. Middletown. 10:00AM.

18—Autism 101. Autism Delaware Newark and Lewes offices. 7:00-8:30PM. R.S.V.P.: Heidi Mizell or Annalisa Ekbladh at (302) 224-6020.

Autism Delaware Junior Golf

This course is designed for youth (ages 8-29) and limited to six participants only.

For five weeks this fall, your child will learn golf techniques as well as personal skills related to golf course etiquette.

Where? **Rookery South Golf Club**

27052 Broadkill Rd., Milton DE 19968

When? **Mondays or Wednesdays**

4:30PM or 5:15PM

Preregistration is required!

Complete the application available at autismdelaware.org, and submit the completed application before August 25.

All information provided or published by Autism Delaware™ is for informational purposes only. Reference to any treatment or therapy option or to any program, service, or treatment provider is not an endorsement by Autism Delaware. You should investigate alternatives that may be more appropriate for a specific individual. Autism Delaware assumes no responsibility for the use made of any information published or provided by Autism Delaware.



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Save the date:

Friday, September 22

7:00-11:00PM

Blue Jean Ball

Denim & Diamondspresented by Hertrich Toyota

oresented by Hertrich Toyota

At Delaware's first and only awardwinning winery, Nassau Valley Vineyards 32165 Winery Way, Lewes DE 19958

With music by Delaware's own Love Seed Mama Jump!

Live and silent auction proceeds benefit Autism Delaware's programs and services. The Blue Jean
Ball has a new
theme—Denim &
Diamonds—and
two new co-chairs.
Shawn Dougherty,
Esq., and Lauren
Fritz-Mariner have
roots in southern
Delaware and are
taking time out of
their hectic schedules to make this
year's autism auction the best ever.



Shawn Dougherty, Esq. Weik, Nitsche & Dougherty



Lauren Fritz-Mariner Wealth Management Advisor Merrill Lynch

AutismDelaware.org