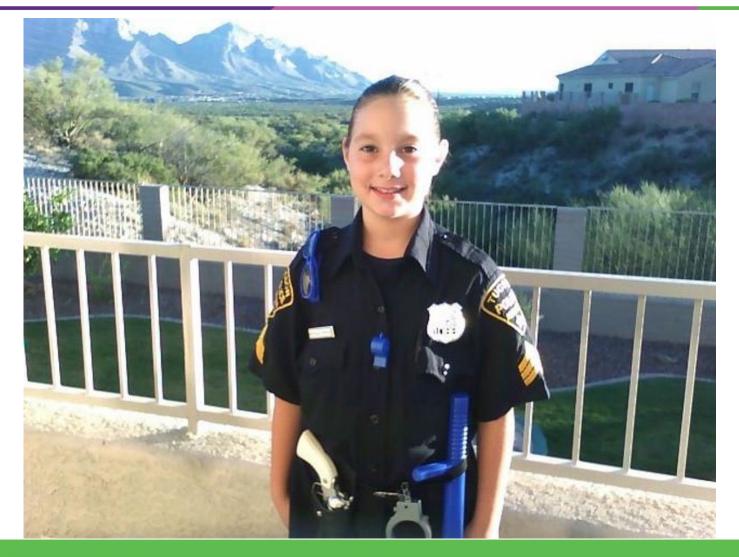


PWSA | USA 2023 NATIONAL CONVENTION

June 21 - 24, 2023 • Orlando, FL

OH NO!!!! FIVE - O





PRADER-WILLI SYNDROME AND LAW ENFORCEMENT

- THIS COURSE WILL PROVIDE INTRODUCTORY INFORMATION ON HOW TO BEST PREPARE FOR AN INCIDENT INVOLVING A FAMILY MEMBER OR STAFF AND LAW ENFORCEMENT
- PREPARATION BEFORE A CRISIS SITUATION IS CRITICAL FOR BOTH LAW ENFORCEMENT AND THE FAMILY IN ORDER TO PROVIDE THE PERSON WITH PWS THE BEST SERVICE AND POSITIVE OUTCOME POSSIBLE

FAMILY AND POLICE WORKING AS ONE

- How to accomplish a positive outcome
- How to best work with law enforcement
- How and who to contact your police department
- How to educate your local police department

- What to do if the person with PWS is arrested
- What to do if family is accused or arrested
- What is law enforcement's role and expectations
- What are civil remedies and how do they apply to your family



PREPARATION IS KEY!

- Make sure family and providers completely understand PWS AND the individual with PWS (they are 2 separate things)
- Have continued training of outside providers and debrief all incidents. Determine the "triggers." They are there
- Educate neighbors, day program staff, school staff all of them! Anyone who could have contact with your loved one. Think outside the box
- (circle K close by; FOOD DELIVERIES, AMAZON)



GETTING READY

- Know your PWS person! The good, the good, the bad and the ugly
- Compile a folder and include pamphlets on PWS along with a small personal bio on them that describes triggers or things that work or don't
- Include extended family if they are involved. Everyone needs to be on the same page!!

Partnering with Police

- Determine what agency services your home or business
- Contact the community resource sergeant or officer of that area
- Brief that sergeant or officer about your home or facility
- Inquire if they have a Crisis Intervention Team

- Request a meeting with the supervisor and a Crisis Intervention Team Leader or liaison
- See if you can make it for a time where shifts overlap
- Gather all necessary educational material together and make folders



Meeting Day

- Have critical family and providers present
- Provide them with information on PWS but don't overload them
- Provide them information about your child
- Explain the issues law enforcement encounters with our population. Theft, allegations of abuse/neglect, running away MELT DOWNS
- Show them the blue form and where it's kept



Law Enforcement Blue Form

ATTENTION LAW ENFORCEMENT

PRADER-WILLI SYNDROME DIAGNOSIS

NAME AND DATE OF BIRTH

PRADER-WILLI SYNDROME IS A DEVELOPMENTAL DISABILITY

IT CAUSES COGNITIVE AND BEHAVIORAL ISSUES THAT CANNOT BE CONTROLLED BY THE CLIENT. THEY HAVE AN INSATIABLE APPETITE AND WILL SEEK FOOD.

_____ HAS A ___IQ AND FUNCTIONS AS A ___ YEAR OLD

(NAME) WILL BE VERBALLY AGGRESSIVE BUT WILL NOT INJURE SELF OR OTHERS. KEEPING THEM IN A SAFE LOCATION WHILE THEY WORK THROUGH THEIR MELTDOWN WILL HELP AS WILL NOT ASKING THEM ANY QUESTIONS DURING THIS TIME, AS THAT PROLONGS THE TANTRUM. (or you can put the opposite, ie: aggressive and what to do)

PWS (NAME) MUST HAVE FOOD LOCKED FROM THEM AT ALL TIMES. IF THEY GET INTO FOOD UNSUPERVISED, IT IS LIFE THREATENING

(NAME) WILL LIE ABOUT (food or whatever)

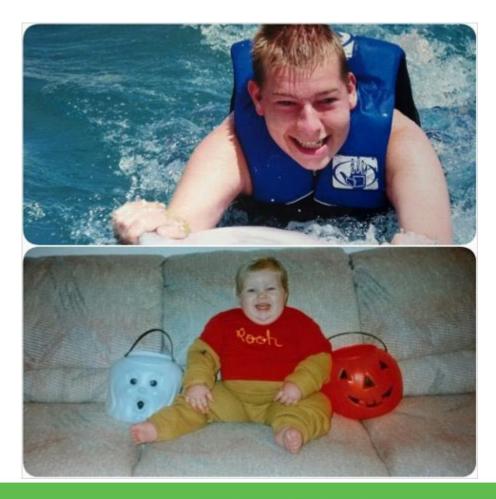
FAMILY HAS PWS INFORMATION AVAILABLE IF THERE ARE FURTHER QUESTIONS

Meeting Day

- Give them a walk through of the homes living area
- Show them the kitchen and thoroughly explain why locks are there
- Show them any other locking or alarm systems to assure the safety of the person with PWS
- Ask if there could be a point of contact officer for non-emergency issues. This may not always be possible
- Inquire about a premise entry
- Find out what Law Enforcement expectations are. They are not the same as ours all the time

Evolution of PWS

Victor at 3 and at 19



Victor in Las Vegas for his 21st birthday!!





Hello Neighbor!

- One of the biggest call generators for police is neighbor problems. Generally, because there was never any communication
- Make sure that you introduce yourself to your neighbors and educate them on PWS
- Give them emergency contact information
- Give them the PWS overview pamphlet
- Assure them that you want to be a good neighbor and are open if there are questions or concerns
- Ask that your loved one causes an issue, for them to contact you immediately so that it can be addressed
- This includes the local mini-market or businesses that may be in your area; calling the pizza or food delivery businesses
- Ask that they only contact police in an emergency or if they cannot contact you

The Day Has Come...Someone Called 911

- The day will come when police show up at the home or in a public place. It will either be a crisis situation or not
- If it is a crisis situation, the police will NOT have the time to go over the details of PWS. They will need to address any threat and make the situation safe. Only then will they be able to discuss resolutions



911 Outcomes

- The officer will resolve the issue and make a report of what occurred.
- The officer will feel that there is a safety concern and contact APS or CPS for guidance and potentially placement
- The officer will transport your child/adult to the hospital for involuntary committal

- The officer will advise that no arrests will be made but that either your child or another is a suspect and detectives will follow up
- The officer will make an arrest of either your child/adult or another.
 This could be through a field release or an in custody arrest



Non-Criminal Situations

- Running away (can be a status offense in some states if a juvenile)
- Mental health break
- Danger to self or others
- Other specific to jurisdiction



Criminal Situations

- Disorderly conduct
- Assault or aggravated assault
- Theft (in and out of home)
- Criminal Damage
- Burglary
- Sex crimes
- Other



Your Child Has Been Arrested

- Is there guardianship in place and how that plays in criminal court
- Field release vs in custody
- Misdemeanor vs Felony
- If a felony, do an attorney consult. Notify
- Contact PWSA-USA so that the LE liaison can get involved. The sooner the better
- What PWSA | USA can do to help



Family Has Been Arrested, NOW WHAT?

- Generally happens with lack of education
- Don't panic, easier said than done but we have been successful
- Field release vs In custody
- Know your rights!! May need representation.
- If you have a local police liaison, have someone from the home contact them
- Contact the 24 hour PWSA-USA line to speak with crisis counselor
- If the right professionals are involved from the BEGINNING, the prosecutor can be educated and has the authority to drop the charges on most cases.
- The above also helps if CPS or APS is involved

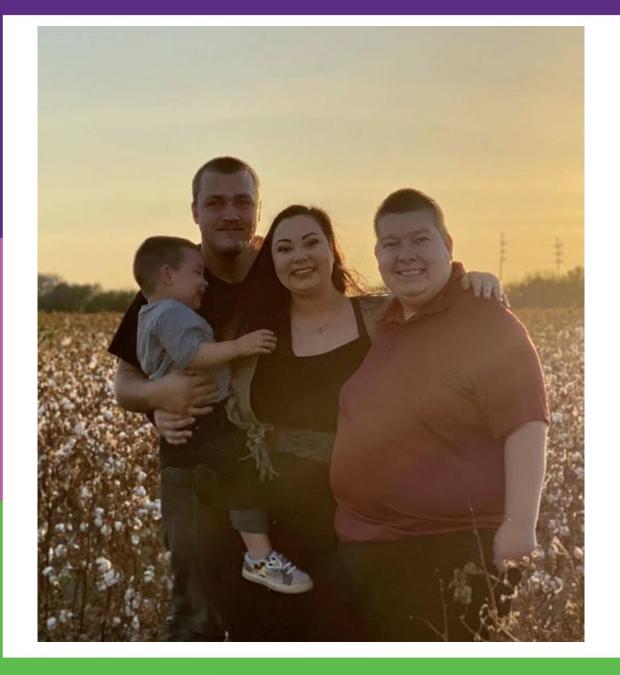
Civil Remedies

- Can be in lieu of criminal charges
- Can be in conjunction with criminal charges
- May have to pay a fee to the company (shoplifting incident)
- May dictate that the person cannot return to that store. If they do they will be criminally prosecuted
- If arrested can ask for a misdemeanor compromise (doesn't work with felonies)



Missing Person

- Call 911 immediately AND SOMEONE STAY AT THE HOME
- THOROUGHLY CHECK THE HOME AND ALL OF THE HIDING SPOTS
- Have current photo
- Have fingerprints and/or DNA to give to police
- Have an overview of this person IQ and function age, medications, PWS specific concerns etc.
- Do they carry a phone or have a GPS device? If so advise police so they can ping it
- Have they done this before? Where have they be found or gone in the past?
- Known obsessions video store; grocery store; Verizon store; riding the city bus
- Contact family or friends that they communicate with?
- Contact or have another family member contact neighbors (this is where we find most of our folks) FOR PW
- What about social media? FB; Instagram; Twitter/ Snapchat







THE DARK WEB

How parents can help their child or adult from becoming a victim

Social Media Concerns

People with intellectual disabilities are more susceptible to exploitation and abuse and the rise of the internet only increases vulnerability.



TWENTY-ONE APPS PARENTS SHOULD KNOW ABOUT





AFTERSCHOOL an anonymous app that has been removed twice from the AppSore because of threats and arrests. Messages often include bullying & pornography.

ASK.FM is know for cyber

users to allow anonymous people to ask them questions.

bullying. The app encourages



HOT OR NOT encourages users to rate your profile, check out people in their area, and chat with strangers. The goal of this app is to hook up.



SNAPCHAT While the app promised the users can take a photo/video and it will disappear, new features including "stories" allow users to view content for up to 24 hours. Snapchat also allows users to view your lo cation.

"addicting" video chat app that allows users to meet people all over the world in just seconds. Reviewers say they have been confronted with racial slurs, explicit content, and more check out people in their area, and chat with strangers. The goal of this app is to hook up.



TANGO social networking app that uses geolocation. Encourages users to talk to strangers and since app utilizes location strangers can get access to your child's location if they are using the





BADOO is a dating and social networking app where users can chat, share photos and videos and connect based on location. While the app is intended for adults only, teens are know to create



KIK allows anyone to contact and direct message your child. Kids can bypass traditional text messaging features. KIK gives users unlimited access to anyone, anywhere, anytime,



TBH networking platform where users anonymously answer questions about their classmates. Promotes bullying and targeting of





BUMBLE is similar to the popular dating app "Tinder" however, it requires woman to make first contact. Kids **BUMBLE** to create fake accounts and falsify their age. only, teens are know to create



LIVEME is a live-streaming video app that use geoloca-tion to share videos so users can find out a broadcasters exact location. Users can earn "coins" as a way to "pay" minors for photos.



TIKTOK is a new mobile device app popular with kids used for creating and sharing short videos. With very little privacy controls, users are vulnerable to cyber bullying and explicit con-



BURNBOOK anonymous app for posting text, photos and audio rumor messages about



MEETME is a dating app that allows users to connect with people based on geographic proximity. As the apps's name suggests, users are encouraged to meet each other in person.



WHATSAPP is a popular messaging app that allows users to send texts, photos, voicemails, make calls and video chats worldwide. Whatsapp uses the internet connection on your smart phone and computers.







WICKR instant messaging apps allow users to exchange end-to-end encrypted and content-expiring messages, including photos, videos, and file attachments and place end-to-end encrypted video conference calls.



WHISPER is an anonymous social network that promotes sharing secrets with strangers. It also revels a user's location so people





CALCULATOR% is only one of SEVERAL secret apps used to hide photos, files and

GRINDR is a dating app

geared towards gay, bi and

transgender people. The app gives users options to chat,

share photos and meet up

based on a smart phone's GPS



MYLOL designed for students 13-19 years old. **Built in features of MyLOL** encourage users to send private messages to random strangers.



SKOUT is a location based dating app and website. While users under 17 years old are unable to share private photos, kids can easily create an account using a different age.





APPS PARENTS SHOULD LOOK FOR ON THEIR CHILDREN'S PHONES

- Plenty of Fish: A popular free dating app and website that encourages chatting with strangers. It allows users to browse profiles based on location.
- HILY: A dating app where users can browse photos, engage in chats, send private videos and more. Based on the GPS location of a mobile device, strangers can arrange to meet up locally.
- Zoosk: A location-based dating app and website similar to many others. The app is available in 80 countries and utilized a 'carousel' feature which matches users with random strangers.
- Mocospace: A free social networking and dating app. Users can connect with strangers worldwide via text messages or voice calls.
- Best Secret Folder: Specifically meant to hide photos and videos. According to app store descriptions, it features password protection, decoy videos and alarm settings.
- Monkey: A live video chat app that connects users to random strangers worldwide, offering group chat and private message options. It claims to be rated for ages 12 and up but has "mild sexual content and nudity."
- MeetMe: A dating social media app that connects people based on location. Users are encouraged to meet in person.
- WhatsApp: A messaging app that allows texts, video calls, photo sharing and voicemails with users worldwide.
- Bumble: Similar to Tinder, but requires women to make the first contact. Law
 enforcement says kids and teens can create fake accounts and falsify their age.
- Live.Me: A live-streaming app that uses geolocation to share videos. The sheriff's office said users can earn "coins" to "pay" minors for photos.
- Ask.FM: The sheriff's office said this app lets users ask anonymous questions and is known for cyberbullying.
- . Grindr: A dating app geared toward the LGBTQ community based on user location.
- TikTok: A new app popular with kids lets users create and share short videos. Law
 enforcement said the app has "very limited privacy controls" and users can be exposed to
 cyberbullying and explicit content.
- Snapchat: One of the most popular social media apps in the world. Snapchat lets users take and share photos and videos. The app also lets people see your location.
- Holla: This self-proclaimed "addicting" video chat app lets users meet people in seconds.
 Law enforcement said users have seen racial slurs and explicit content.
- Calculator+: Police say this is one of several apps that are used to hide photos, videos, files and browser history.
- Skout: A location-based dating app that is supposed to prohibit people under 17 from sharing private photos. However, police say kids can easily create an account with a different age.
- Badoo: A dating and social media app where users can chat and share photos and videos based on location. Police say the app is supposed to be for adults only, but they've seen teens create accounts.
- Kik: Police say kids can bypass traditional text messaging features using this app. Kik
 "gives users unlimited access to anyone, anywhere, anytime," the sheriff's office said.
 The Kik app is actually going away, although there's no clear date for when it will shut down.
- Whisper: An anonymous social network that lets users share secrets with strangers.
 Police say it also shows users' location so people can meet up.
- Hot or Not: The app lets users rate profiles, check out people in their area and chat with strangers. Police say the goal of the app is to hook up.



Michigan State University Study

- 1/3 said they would send their photo to online person and would arrange to go to the home of a person they met online AND keep that relationship from parents/caregivers.
- 86% of adults used social networking such as FB daily, typically without supervision.
- That participants shared a large amount of identifiable info on their profiles and ARE LIKELY TO AGREE TO ENGAGE IN SOCIALLY RISKY BEHAVIOR!

Things to Consider

- What can YOU do within the boundaries of the laws of your state, federal laws.
- With little statistics on this with PWS, how can safety training be implemented for our population that will protect their right to least restrictive, while keeping them safe.
- What does that look like?



The grooming line







Abusive

Appendix 3 The grooming line

Targeting stage

■ Observing the child/ young person

- Selection of child/ young person
- Befriending being nice, giving gifts, caring, taking an interest, giving compliments, etc
- Gaining and developing trust
- Sharing information about young people between other abusive adults

Friendship forming stage

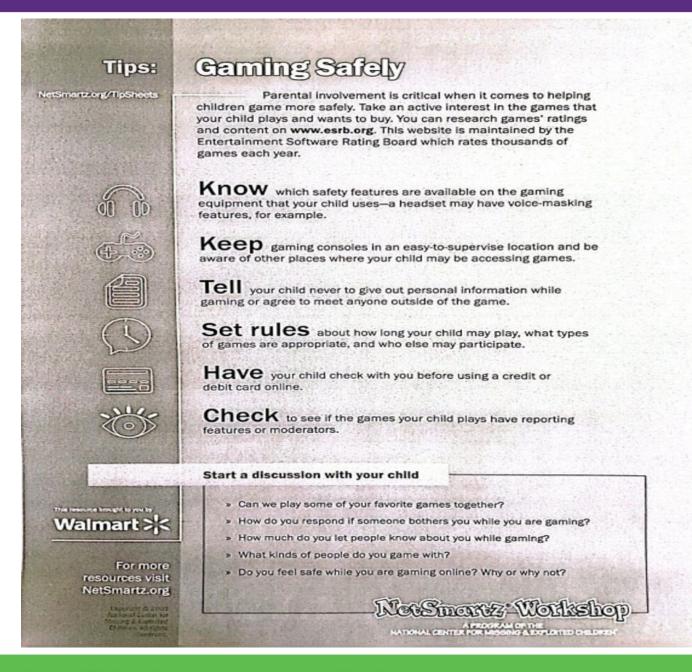
- Making young people feel special
- Giving gifts and rewards
- Spending time together
- Listening and remembering
- Keeping secrets
- Being there for them
- 'No-one understands you like I do'; being their best friend
- Testing out physical contact accidental touching
- Offering protection

Loving relationship stage

- Being their boyfriend/girlfriend
- Establishing a sexual relationship
- Lowering their inhibitions eg showing them pornography
- Engaging them in forbidden activities - eg going to clubs, drinking, taking drugs
- Being inconsistent building up hope and then punishing them

relationship stage

- Becomes an 'unloving' sexual relationship
- Withdrawal of love and friendship
- Reinforcing dependency on them - stating young person is 'damaged goods'
- Isolation from family and friends
- Trickery and manipulation 'you owe me'
- Threatening behaviour
- Physical violence
- Sexual assaults
- Making them have sex with other people
- Giving them drugs
- Playing on the young person's feeling of guilt, shame and fear





Dangers of Sexting

It is illegal!

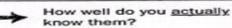
It's illegal for anyone to possess or send naked photos of a minor (someone who is under 18 years old), and anyone can be arrested for distributing child sexual abuse material (CSAM) including videos Wink about or photos of minors in sexual situations.

Before sending intimate pics or vids to:



It is harmful long-term

- Pictures can be saved and shared and may be used as "revenge porn"
- Predators can use sexts to control youth and remove their personal safety boundaries through intimidation. This is called



If they are your GF/BF, how do you know they won't want to send out revenge pom or post it on websites after the relationship ends?

SEXTORTIO

according to NCMEC, sextortion predators typically want to acquire more and more explicit material from the victim, get money or goods from them, or meet in person in order to engage in sex with the victim.





You may become a victim of sextortion, which is a form of sex trafficking.

You may be intimidated into meeting with them, meaning you may be physically endangering yourself.



How online grooming takes place and it can

- . They try to appear familiar
- They start <u>developing trust</u>
- They try to establish secrecy
 - They slowly erode boundaries
 - . They use direct intimidation eleme? 10 of

9 ook our Social Media Chat apps Games

Take ACTIONI

- Stop talking to them
- Block them everywhere
- Report the person to the app
 - Save screenshots of your conversations with them
 - Report them to National Center for Missing and Exploited Children (NCMEC) CyberTipLine.org
- Tell a safe adult!

YOU ARE NOT THE CRIMINAL,

online rule #1

Assume that nothing you share on the internet or text messages is private.

That data is stored on the cloud the moment you send it. Even deleted things can be found again.

Porn Alert:

- Porn can noticeably change how a person dresses or acts, and predators are watching
- 2. It negatively impacts the way someone views sexuality and can harm their relationships
- By making changes to the brain, it becomes extremely addictive

Watch

Video



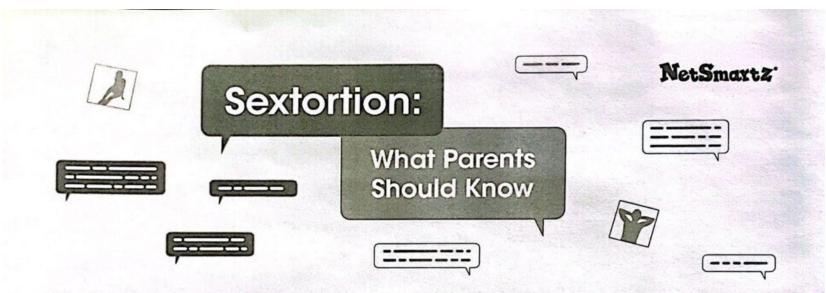


PWSA | USA 2023 NATIONAL CONVENTION

It can hurt you.

SE 3. F 1 45





You've likely heard of sexting – sharing and receiving sexually explicit messages and nude or partially nude images by text or through an app. Though sexting can be part of normal adolescent sexual development, there are also risks, particularly sextortion.

Sextortion:

A type of blackmail used by offenders to acquire additional sexual content from the child, coerce them into engaging in sexual activity, or to obtain money from the child.

Who Are the Perpetrators?

Often, victims know their extorters. They are current or former romantic partners. They may hold an initial sexual image that was sent intentionally by the victim and are now using it to get more content; threatening to spread the picture to friends and family if the victim does not comply.

60% of the is known

of the time, the blackmailer is known to the victim.

Other times, the offender was met online. This could be a lone-actor or a coordinated group of extorters who work together to target and elicit explicit content from their victims. This type of extorter may request additional content (often of an increasingly explicit nature) or money.

Copyright © 2020 National Center for Missing & Exploited Children. All rights reserved.





How Does it Happen?

Sextortion can happen at the hands of both peers and unknown, online offenders.

When It's an Unknown Offender

Approach

Offenders often approach a child on social media after using it to learn about the child's interests, friends, school, family, etc.

Move platforms

It is common for offenders to make initial contact with a victim on one platform, then ask them to move to a second or third platform, usually those with encrypted messaging systems in order to make tracking their crime more difficult.

Coerce

This includes using tactics like:

- » Initially offering something of value such as money or drugs in exchange for a sexual image
- » Pretending to work for a modeling agency
- » Developing a false rapport with the child

- » Secretly recording explicit videos/ messages during chats
- » Threatening to physically assault the child or his/her family
- » Using multiple identities to contact the child

- » Pretending to be younger and/or a member of the opposite sex
- » Hacking accounts to steal sexual images, or
- » Threatening to commit suicide if no images are sent

When It's Someone Known

Acquire the Image

Often, the extorter is an exromantic partner who may have received the image deliberately from the victim while involved in a relationship.

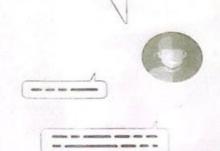
Threaten

The extorter may use the threat of spreading the image to force the victim into staying in/returning to the relationship after it has ended, or to acquire additional sexual content.

Persist

VS

The harassment rarely stops if a victim complies with the extorter's demands.



Copyright @ 2020 National Center for Missing & Exploited Children. All rights reserved.



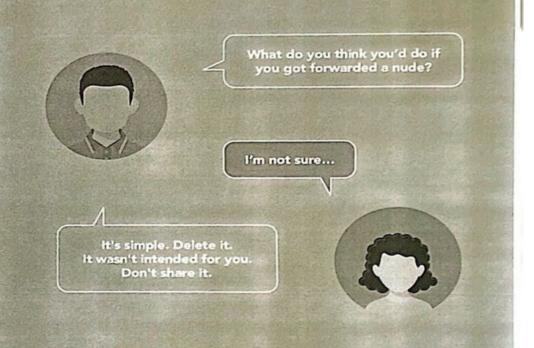
What Can I Do About It?

Talk About Technology

Children should grow up expecting that their parents are a part of their digital lives. Regular check-ins about their online interactions should be the norm. Include children in setting rules and limits for their tech-time.

Talk About Sexuality and Relationships

Talking about your family's expectations and values regarding sex and relationships is an important first step. These conversations should happen regularly. Be sure to discuss the characteristics of healthy relationships, such as having and respecting boundaries and practicing consent. Explain that both pressuring someone and being pressured into sexual behaviors that are uncomfortable or unsafe are NOT OK. Similarly, help children understand that they should never forward sexts they may receive from others. Limiting the image's spread reduces the risk of it falling into dangerous hands.



NetSmartz

For more resources, visit MissingKids.org/NetSmartz

Copyright © 2020 National Center for Missing & Exploited Children. All rights reserved.







NetSmartz

Cyberbullying Unplugged

Cyberbullying is the use of technology to tease, humiliate, threaten and/or harass someone. It can take place through text messaging or social media. Cyberbullies might send mean comments, post embarrassing photos, or share private information about someone to humiliate or mock them online. Even if your child isn't being cyberbullied, remind them that it is everyone's job to prevent bullying and encourage them to take a stand.

Spot It A child who is being cyberbullied may

- · Avoid using the Internet
- Seem stressed when getting an email, text, or other message
- Withdraw from family and friends
- Resist attending school and social events
- Show signs of low self-esteem like depression or fear
- Have declining grades
- Stop eating or sleeping
- In serious cases, consider suicide

Deal With It If your child is being cyberbullied, teach them to

- Not respond
- Save the evidence

Any online harassment that is sexual in nature should also be reported to Report.CyberTip.org.



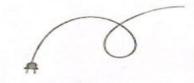
- . Meet with school administrators to discuss a plan of action and their builtying/cyberbullying policy
- Talk about the situation with the bully's parent or guardian

Stand Up To It If your child sees someone being cyberbullied, tell them to

- Not forward embarrassing photos or messages
- Not comment on insulting or harassing posts
- · Report it to the website or app
- . Tell a teacher at school if it involves a classmate
- . Support the victim by being a good friend and showing the cyberbullies they won't join in



For more resources visit MissingKids.org/NetSmartz/Resources Copyright © 2010-2019 National Center for Missing & Exploited Children. All rights reserved





HUMAN TRAFFICKING

- Def: The recruitment, transportation, transfer, harboring, or receipt of persons by improper means (such as force, abduction, fraud, or coercion) for an improper purpose including forced labor or sexual exploitation.
- We think sex trade....not always, could be SSI/SSD fraud; domestic servitude. This is often accomplished through online relationships.

You, the Internet & Predators



If you use any of these...

---READ ONE

"Sex trafficking only happens when someone gets kidnapped."

According to the National Center for Missing and Exploited Children, there are 750,000 predators online worldwide at any given moment. What is Sex Trafficking - it occurs when someone under 18

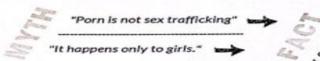
years of age is used in any sexual act in exchange for anything of value, such as food,

shelter, transportation, drugs, or protection. This includes any sex act such as stripping, prostitution, or taking sexual videos or photos.

More often than not, sex traffickers end up being people who seem trustworthy—that cute older guy in your DMs, the girl from the coffee shop you've been texting with, or unfortunately, even a well-known family member.

Instead of kidnapping their victims and keeping them in a dungeon, they use their victim's love and trust to <u>manipulate</u> them into doing whatever they want, including sexual acts, oftentimes without anyone around them knowing something is wrong.





Any photos or videos that are sexually explicit and include minors are considered sex trafficking.

Predators will try to talk to any girls or guys who will engage in conversation. What seems like harmless texts and asks, can become something very harmful in the long run.

Protect Yourself

aka, be more elever than they

Make sure all of your accounts are private

Don't use the same username in every app and game

Only friend and talk to those people <u>you know</u> (in real life!)

Don't accept digital \$, tips, or gifts <u>in exchange</u> for any picture

All personal info (school, city, phone #, etc.) is private info

Monitor your followers and block people you don't know

Turn your location services off!



Friend Requests

If the person's account is private and you don't recognize their profile pic or username, don't accept, and don't reply to them. It's not worth the risk!

Check out who they are following.
This can be a huge indicator of someone's intentions.

Look into their bios. Although some traffickers are good at hiding their intentions, others are not so subtle.

YouthOnline.SharedHope.org

But wait. There's more! Scan QR code with your 🔲

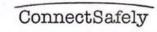
Inited in Hope FOR PWS

Online Resource Sites:

· socialwork.asu.edu/stir/training



- missingkids.org/NetSmartz
- · urbandictionary.com
- internetsafety101.org/parentsguidetosocialmedia
- NCMEC
- · connectsafely.org





- protectyoungeyes.com/protect-app/
- sharedhope.org/resources/
- · stopbullying.gov stopbullying.gov





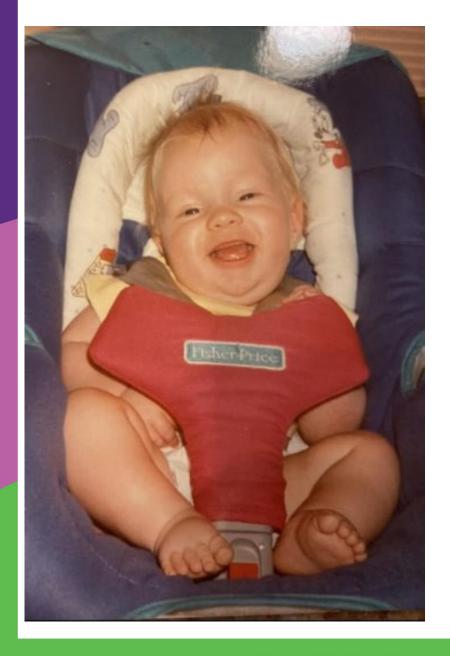




Safety must be the priority for the PWS Population











TAMMIE PENTA TPENTA1@GMAIL.COM 520-343-4879





THANK YOU



www.pwsausa.org



Info@pwsausa.org



(941) 312-0400