myFace

Transforming Lives:
Creating Building Blocks for Home, School, and Social Connections for Children With Craniofacial Diagnoses

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Welcome and Introductions

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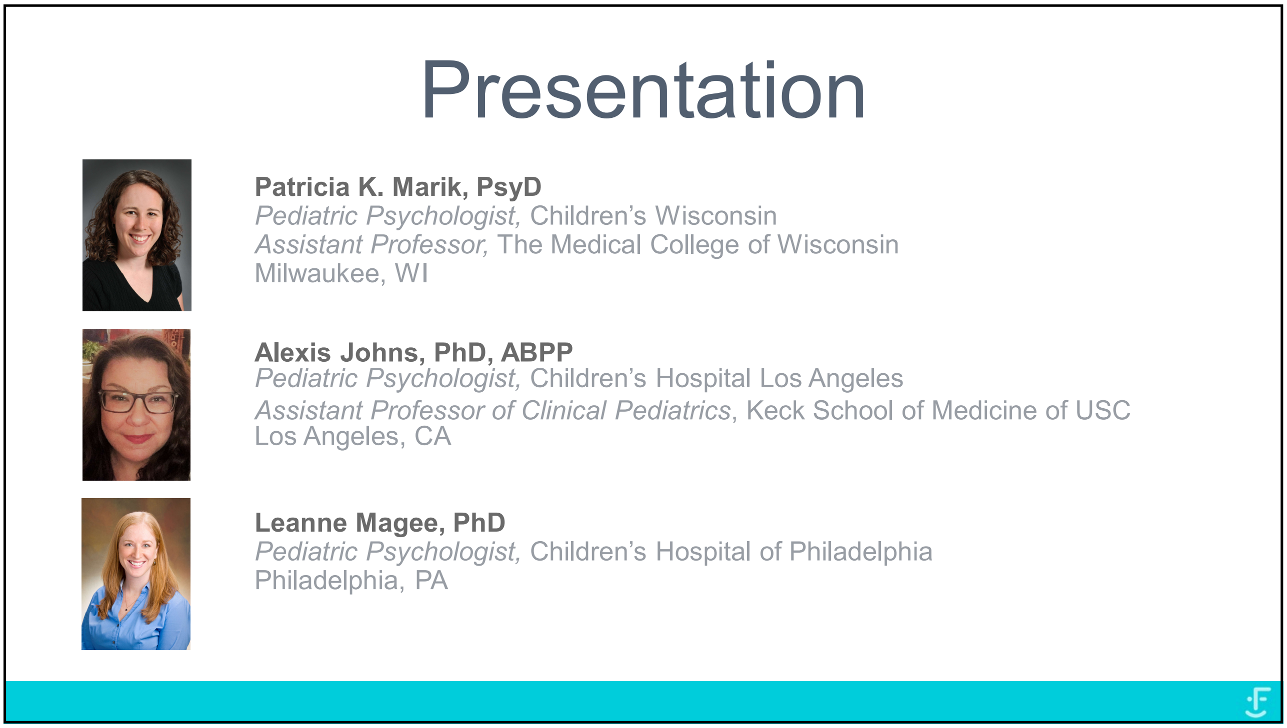

Presentation

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Home Building Blocks

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- Building your child's understanding of their craniofacial diagnosis
  - Preparing for surgery
- Building blocks for behavior management at home
- Parenting during COVID-19

Parenting During COVID-19

- COVID-19 has impacted children
  - School closures, missed birthday parties, separation from extended family, awareness of parental stress, loss or learning about loss, sports cancellations, milestone celebration cancellations…..
- Children may demonstrate increased aggressive behaviors
- May struggle with emotional regulation
- May become more isolated
- May attempt to alleviate the stress in the home
  - Even toddlers will pick up on parental stress
- May experience increased anxiety
- May attempt to gain control in unhealthy ways
- Previous mental health concerns may be exacerbated

- Surgeries may be postponed
- Medical appointments may be different
- Therapies may be virtual
- ….and so on…

Parenting During COVID-19

- Most important thing a parent can do is listen
  - Ask your children what they already know, what they have heard, etc.
  - Ask what their concerns are
  - Use open ended questions
- Answer questions honestly but in a developmentally appropriate way
- Be clear about the support your child has despite uncertainty
- Emphasize that the pandemic is temporary
- Be aware of news coverage
- Maintain physical activity (as it is safe to do so)
- Establish a schedule/routine

Parenting and Discipline During COVID-19

- Ongoing discipline is important for children’s psychosocial health
  - Consider increasing comfort behaviors (e.g., hugs, etc.) instead of becoming overly permissive
  - Consider possible new negative impact of previous consequences (e.g., removing technology may reduce access to extended family, etc.)
- Model healthy coping yourself
  - Talk about how you are feeling (within limits) and how you coped, label coping behaviors you are using, etc.

Supporting Your Child's Transition to "Post-pandemic" Life

- Remember how much of their life has been during the pandemic
  - 1 year for a 30-year old is 2.86% of their life
  - 1 year for an 8-year old is 12.5% of their life
- Do not make assumptions about how your child feels
- Remember your child is not the same person they were at the start of the pandemic – and that is normal
- Maintain space to listen to your child's fears and excitements
  - Continue to talk about what they are seeing and hearing in the community
- Consider what may be a new trigger for anxiety and make a plan to address this
- Do not try to "catch up" on everything that was missed
- Continue to model talking about feelings and how to deal with them
- Ask your child what new traditions they would like to keep (if possible)

Building Your Child's Understanding of Their Craniofacial Diagnosis

Age	Building blocks caregivers can provide
Infants (0 – 12 months) Toddlers (1 – 2 years)	Attachment is main concern (child has no real understanding of facial difference yet) - Provide care, be present during procedures and hospitalizations, provide comfort, maintain routines - Document your child's medical journey for them - Don't forget about older siblings!
Preschoolers (3 – 5 years)	Begin to notice differences - Start to model/practice responses to questions - Create a space to talk about "highs" and "lows" of each day - Educate other caregivers (daycare providers, etc.)
Early school age (6 – 8 years)	Will notice differences - Check in about peer relationships - Maintain communication with adults who supervise less structured times (e.g., recess, lunchroom, afterschool programming) - Talk about how to respond to questions versus teasing

COVID-19 Considerations:
- Visitor restrictions
- Day care changes
- Impact of masking

Building Your Child’s Understanding of Their Craniofacial Diagnosis

Age	Building blocks caregivers can provide
Later school age (9 – 12 years)	Puberty leads to many changes, may become more critical of appearance - Maintain social contacts - Obtain your child’s input as to what support they want addressing peer concerns - Thank them for sharing difficult things with you - Keep protected “talking time” (can be helpful to do this during an activity, in the car, etc.)
Adolescents	Main concerns may be fitting in and self identity Any difference may be perceived as negative - Encourage participation in medical decision making, appointments, etc. - Allow your teen time alone with their medical team if they would like - Do not minimize social concerns - Keep lines of communication open - Do not offer choices (e.g., about surgeries, etc.) unless either option is acceptable

Preparing Your Child for Surgery

- Information for your child should be given:
  - In a way they will understand
  - To help correct any false thinking
  - To get rid of fears your child may have
  - HONESTLY
- Remember that children are always listening
- Consider a pre-surgical tour if possible
- Prepare siblings
  - Including what the plan is for their care during and after surgery
  - Keep sibling’s schedule as typical as possible
- Stay relaxed but normalize nerves

COVID-19 Considerations:
- Uncertainty may be increased
- Consider role of virtual school (ok to still take a break from school)
- Visitor restrictions may impact hospitalization
- Hospitalization may look different (no child life activities, etc.)

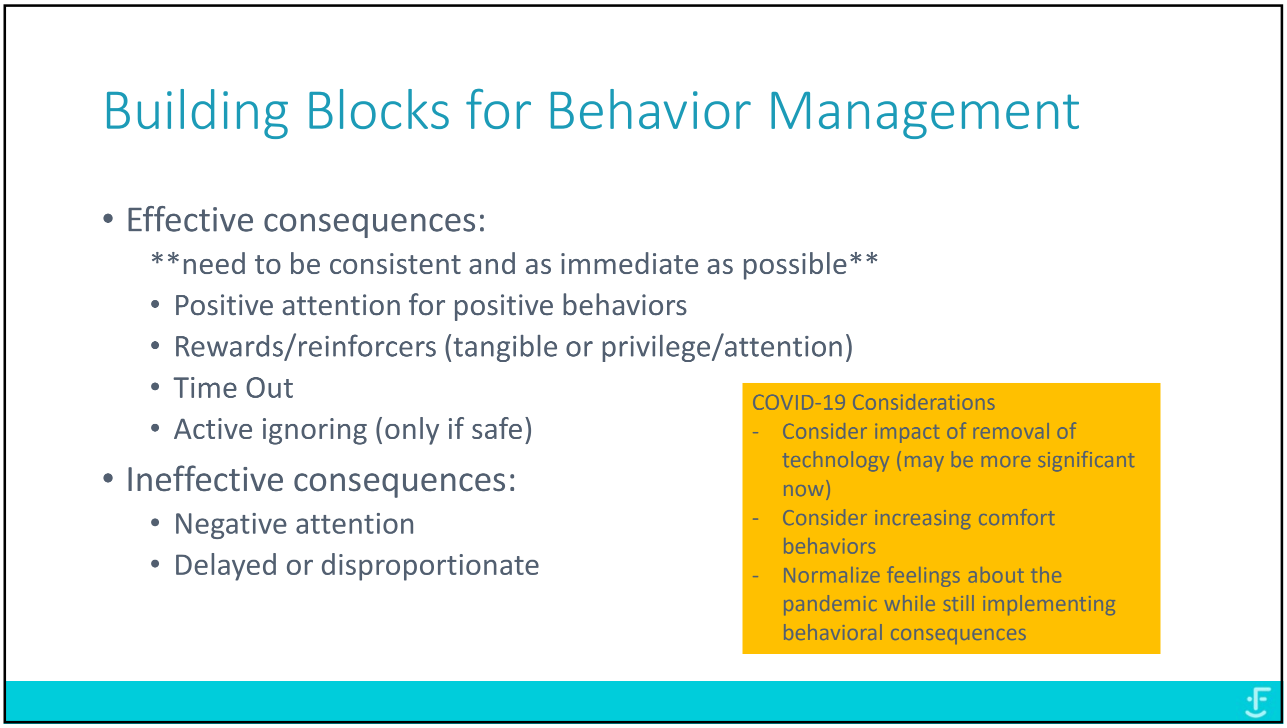
Preparing Your Child for Surgery

Age	Strategy
Infants (0 – 12 months)	- Familiar objects and people are important - Bring a favorite blanket or toy
Toddlers (1 – 2 years)	- Talk about the hospital 1–2 days before surgery - Let your child choose a stuffed animal or toy to bring - Explain what will happen and model exam if needed
Preschoolers (3 – 5 years)	- Talk about the hospital 3 days before surgery - Read books about the hospital together; Engage in medical play - Use simple terms but be honest
School age (5 – 12 years)	- Talk about the hospital 1–2 weeks before - Encourage questions & answer honestly ("teach back" for comprehension) - Explain what your child will see after the surgery (stitches, bandages, etc.)
Teens (13 – 18 years)	- Remember teenagers are focused on independence, privacy & body image - Encourage them to be a part of the decision making (as they like/is appropriate) - Encourage your teen to ask questions and answer honestly - Respect your teens need for privacy

Building Blocks for Behavior Management

- ABC's of behavior management
  - Antecedents: Factors that make a behavior more or less likely (AKA, Triggers)
  - Behavior: Specific action you want to encourage or discourage
  - Consequence: Results of the behavior

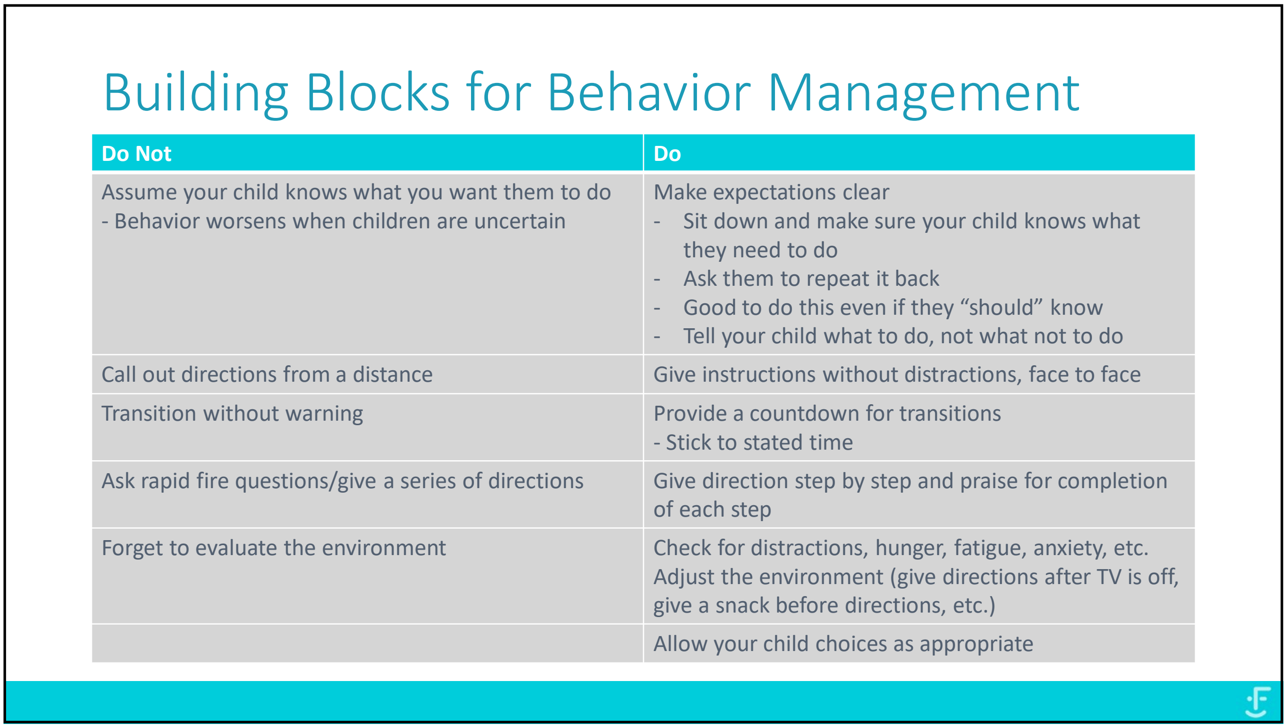
- Behavior + Attention = More Behavior
  - "Catch" your child being good
  - Label praise
  - Ignore negative behaviors (when safe)
    - Do not look at, talk to, touch your child
    - Can "talk to the air" if necessary
    - Make sure to give positive attention as soon as behavior stops/lessens



Building Blocks for Behavior Management

- Effective consequences:
  need to be consistent and as immediate as possible
  - Positive attention for positive behaviors
  - Rewards/reinforcers (tangible or privilege/attention)
  - Time Out
  - Active ignoring (only if safe)
- Ineffective consequences:
  - Negative attention
  - Delayed or disproportionate

COVID-19 Considerations
- Consider impact of removal of technology (may be more significant now)
- Consider increasing comfort behaviors
- Normalize feelings about the pandemic while still implementing behavioral consequences



Building Blocks for Behavior Management

Do Not	Do
Assume your child knows what you want them to do - Behavior worsens when children are uncertain	Make expectations clear - Sit down and make sure your child knows what they need to do - Ask them to repeat it back - Good to do this even if they "should" know - Tell your child what to do, not what not to do
Call out directions from a distance	Give instructions without distractions, face to face
Transition without warning	Provide a countdown for transitions - Stick to stated time
Ask rapid fire questions/give a series of directions	Give direction step by step and praise for completion of each step
Forget to evaluate the environment	Check for distractions, hunger, fatigue, anxiety, etc. Adjust the environment (give directions after TV is off, give a snack before directions, etc.)
	Allow your child choices as appropriate

Time Out

- Set behaviors/consequences ahead of time
- If safe, allow one warning
- Use a predetermined place (best to label this the "Time Out" space versus "naughty space" or something similar)
  - Can have Time Out plan for public places as well
- One minute per age
  - Good to set a timer so that child knows how much longer they have
- Require your child to be calm for Time Out to end
- Quick response
  - After warning, make sure the Time Out is immediate
  - State the reason for the Time Out "You hit your brother. Go to Time Out now."
  - Do not give any other verbal input at this time
  - Be brief and neutral (not emotional)
  - Delayed consequences do not work

General Behavioral Management

- Time Out – Refusals
  - Give a time limit to get into Time Out before it is doubled
    - "If you're not on the Time Out chair by the time I count to three your Time Out will double"
  - Remove desired objects for not doing a Time Out (e.g., cannot watch TV or play video game until Time Out is done)
  - Praise for successful Time Out completion
- Consequences for older children:
  - Remove privileges/objects (e.g., TV, video games, going outside, etc.)
  - Better to provide reinforcement than punishment (e.g., earn privileges as opposed to losing them)
  - For most situations you should re-start privileges at the beginning of the next day
  - Still best for consequences to be as close to negative behavior as possible

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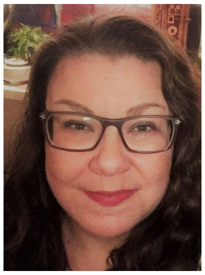
Building Social Connections



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COVID-19 Social Impact & Self-Image

Masks
- Speech
- Hearing loss
- Noticing differences in social interactions

Online Activities
- Extended time focused on faces on camera
- Increased overall appearance awareness

Isolation
- Loss of routine peer contact
- Loneliness
- Increased mental health concerns

Transitioning out of pandemic:
- Anxiety about returning to social settings and variable COVID-19 health concerns
- Self-consciousness of not wearing a mask
- Re-adjustment to school social demands

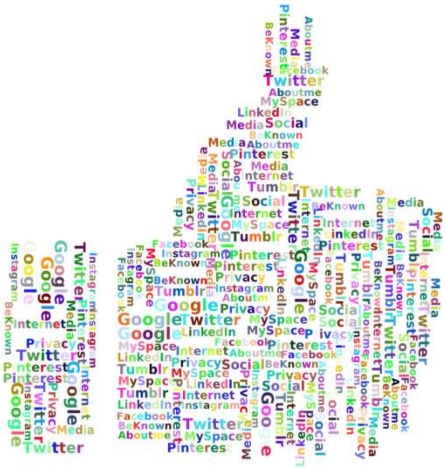
COVID-19 & Cyber Life

- Before COVID-19, screen time was already the **primary** activity in children's daily lives and distance learning added additional time
- Prior to COVID-19, children spent 5 to 11 hours daily on devices, computers, TV, etc.
- Social media use starts by age 10 for 60% of children
- Only a third of children report parental rules for social media use

American Academy of Pediatrics recommends:
- Limit screen time to 2 hours a day (not counting time for distance learning)
- Minimal screen time under the age of two
- Keep devices out of bedrooms
- Establish and model family rules like: no devices at the dinner table, no screen time when possible during homework, and equal time spent in other activities

Social Media Benefits Magnified by COVID-19

- Keep connected to friends and receive social support
- Experience normalization
- Develop new support networks with shared interests/experiences
- Self-expression and promotes creativity
- Identity development



Cyber Bullying

- Texts
- Posts
- Tags
- Videos
- Photos

- Emails
- Webpages
- Chats
- Comments
- Gaming

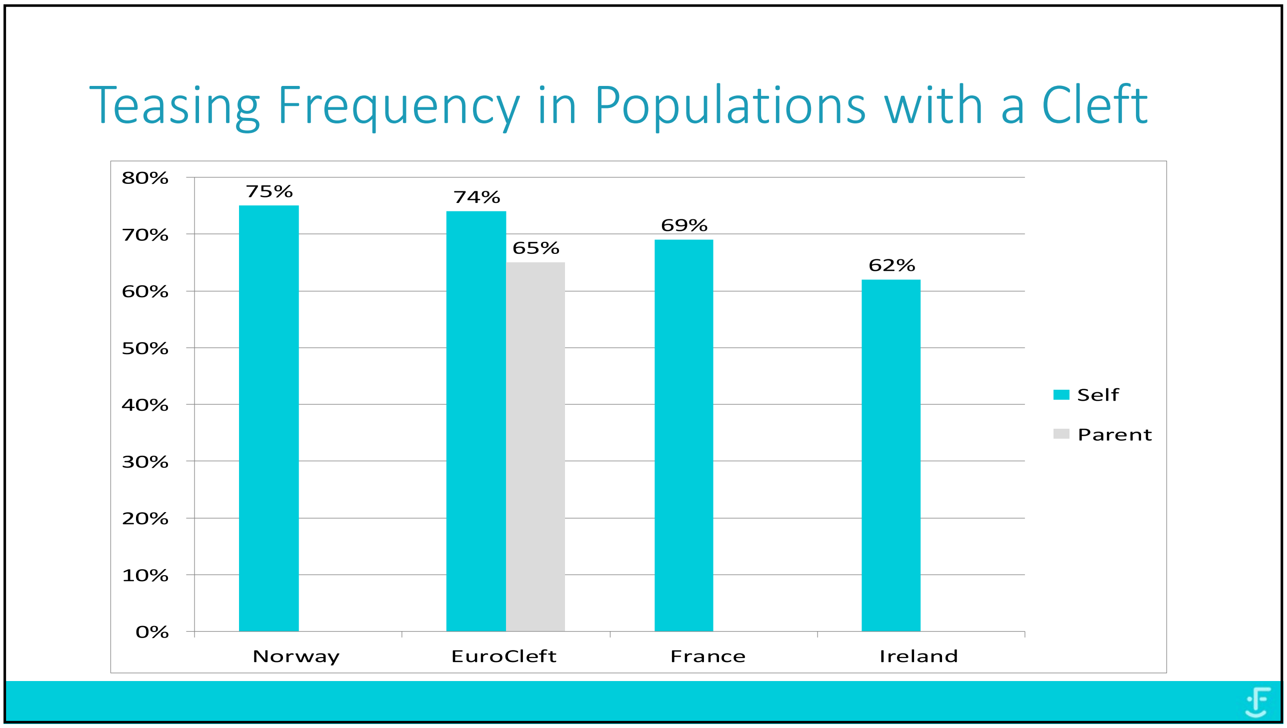
- Unlimited audience size/viral
- Targeted audience possible
- Misleading/anonymous perpetrator
- Possible at any time and endless
- Difficult for adults to supervise
- Hard for law enforcement to investigate
- About 25%–35% of general population
- A 70% increase since COVID-19

Cyber Bullying Caregiver Role

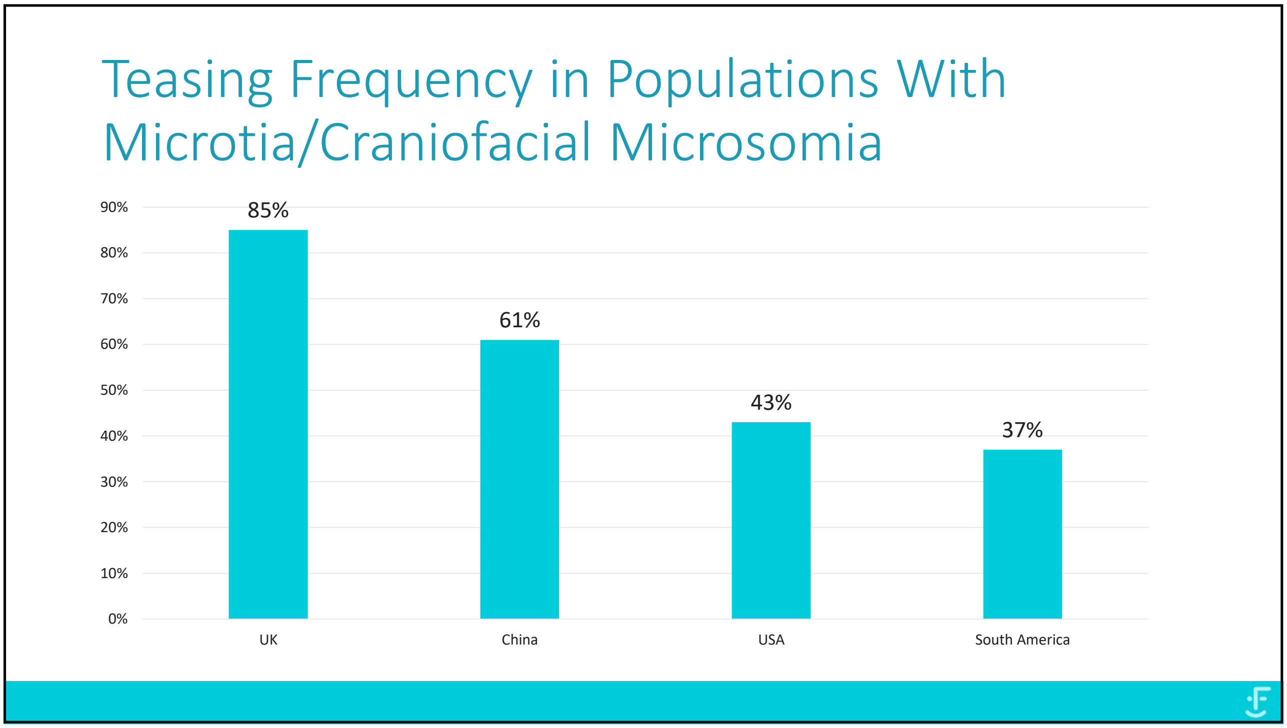
- Teach and monitor screen use openly, while balancing privacy
- Talk about expectations for screen use with the same values set by the family in any situation
- Be empathic and supportive if cyber bullying takes place, rather than dismissive
- Discuss options about how to respond together, including collecting evidence
- Contact the platform administration to remove content, block users, delete accounts, etc., and report on http://www.cyberbullying.us/report
- Seek mental health support for ongoing concerns about children's adjustment

Teasing & Bullying – Returning to School

- Around 35% of youth in the general population report teasing or bullying
- Children with craniofacial diagnoses are more likely to experience teasing
- Teasing tends to start in preschool, peak in middle school, and decline by the end of high school
- If not addressed, bullying can have long-term outcomes on adult adjustment
- Bullying can be physical, but is most often social and verbal – as well as cyber bullying and within distance learning and virtual activities during COVID-19



Teasing Frequency in Populations with a Cleft



Teasing Frequency in Populations With Microtia/Craniofacial Microsomia

Caregiver Role

- Help teach your children the difference between the frequent questions or comments that come out of curiosity and those that are meant to be hurtful
- Regularly check in with children about any teasing across settings
- Balance being protective with children learning adaptive independent coping
- Help your children practice at home how they can handle situations at school
- For school-based concerns that persist, talk to teachers and school administration directly rather than to the students involved or their parents
- If bullying is within context of extended family/friend network, collaborate with family of the perpetrator
- If there are threats of physical aggression or a possible crime (e.g., stalking, blackmail), contact local law enforcement

Medical Language Awareness

- Use neutral/descriptive language with children
- Many medical terms, like abnormality, malformation, and deformation, can have negative connotations and imply that a child is “broken”

Medical Terms	Alternative Terms
birth defect =>	congenital diagnosis diagnosis a child is born with
lip/palate repair =>	lip/palate surgery
fix the lip/palate =>	close the lip/palate
nasal deformity =>	nasal flattening
alveolar ridge defect =>	opening in bone in the gum line

Confident Nonverbal Communication: STEPS

- **Self-Talk**: thinking positive and affirming statements about one's self
- **Tone of Voice**: speaking clearly and at an appropriate volume to be easily heard
- **Eye Contact**: looking at people in the eye when talking and listening
- **Posture**: keeping an upright posture with shoulders back and head up
- **Smile**: showing friendliness and confidence

Kammerer Quayle (2001)

Rehearse Your Response

- **Label:**

I have a cleft lip and palate. • I was born with my top lip open. • This part (pointing) was open when I was born, and the doctor closed it when I was a baby. • I was born with a little ear.

- **Reassure:**

I'm doing great. • I had surgery and I am doing really well. • My doctors are taking good care of me. • I have a few surgeries to go and so far, so good! • I can hear everything with my hearing aid.

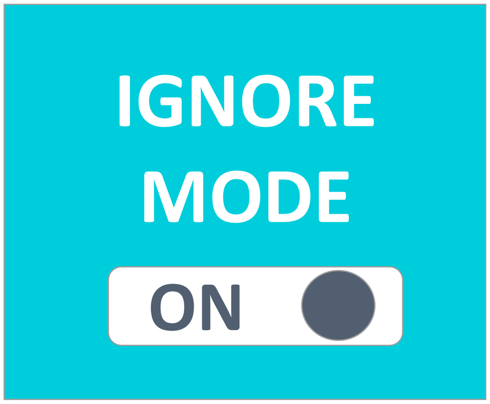
- **Change Topic:**

Thanks for checking in on me. • What's the math homework? • Who's your favorite superhero? • Let's go play tag! • What's for lunch?

Kammerer Quayle (2001)

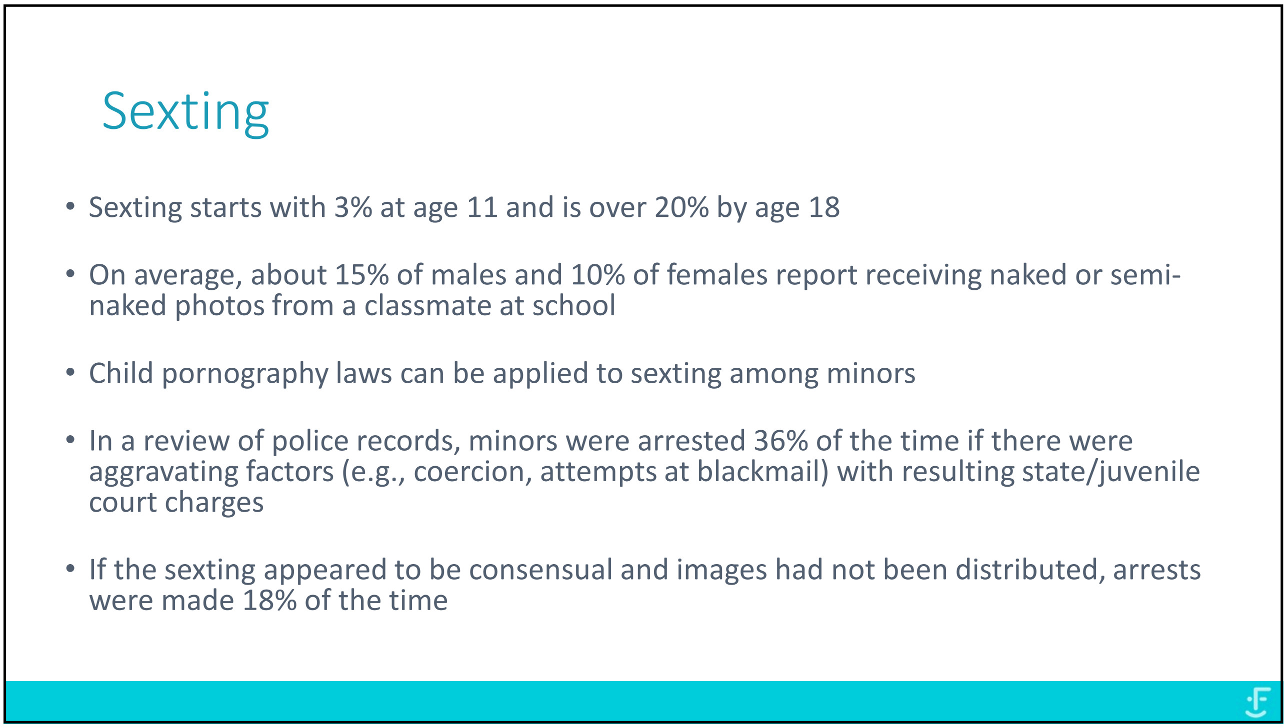
Coach Assertiveness

- **Active** ignoring
- Walk away
- Say “no” or “stop”
- Use friendly humor
- Seek friends’ support
- With trusted people, express feelings
- Get help from an adult



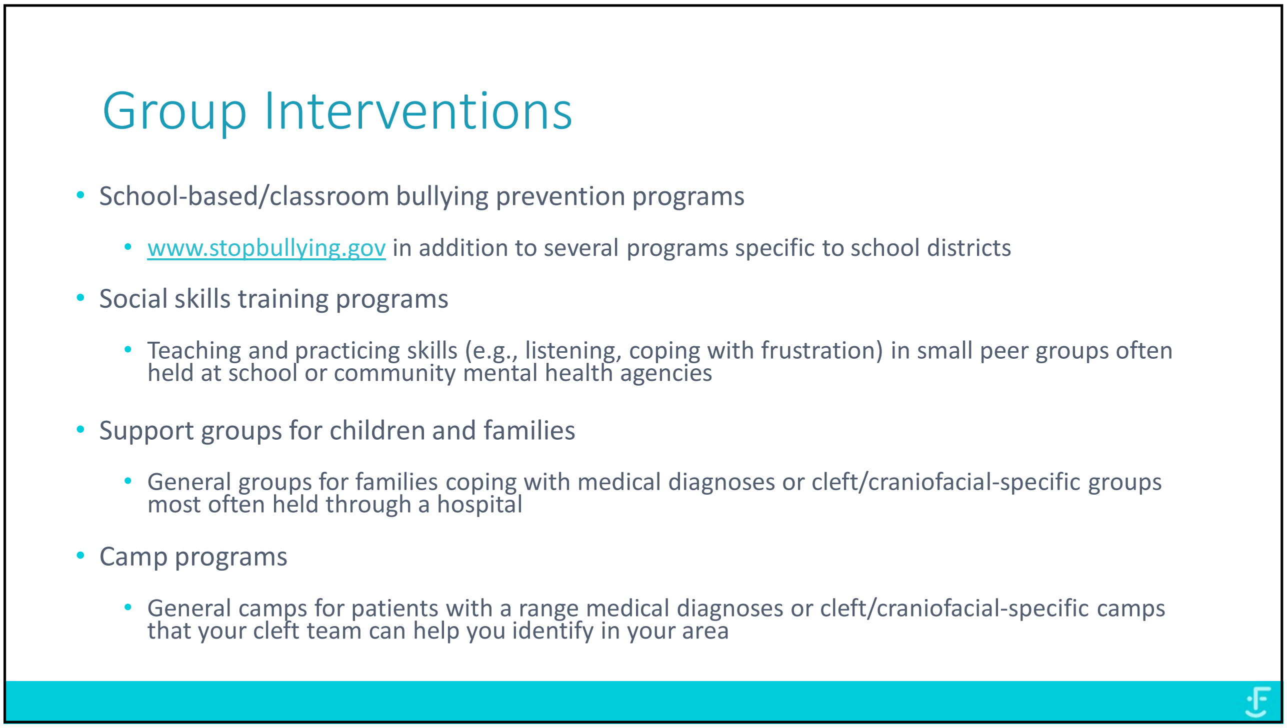
Dating

- Keep open communication in discussing dating and family expectations
- Check in about how your child and their friends are thinking about dating
- Discuss with your child how to talk about their cleft with a date as they would with friends and practice how to respond to different reactions
- One large study found no differences in self-rated romantic appeal for boys with a cleft and a very small difference for girls with a cleft when compared to their peers at age 16
- Consider an adolescent genetic visit to discuss recurrence rates – especially if there has been an assumption of 50/50 recurrence from their biology classes



Sexting

- Sexting starts with 3% at age 11 and is over 20% by age 18
- On average, about 15% of males and 10% of females report receiving naked or semi-naked photos from a classmate at school
- Child pornography laws can be applied to sexting among minors
- In a review of police records, minors were arrested 36% of the time if there were aggravating factors (e.g., coercion, attempts at blackmail) with resulting state/juvenile court charges
- If the sexting appeared to be consensual and images had not been distributed, arrests were made 18% of the time



Group Interventions

- School-based/classroom bullying prevention programs
  - www.stopbullying.gov in addition to several programs specific to school districts
- Social skills training programs
  - Teaching and practicing skills (e.g., listening, coping with frustration) in small peer groups often held at school or community mental health agencies
- Support groups for children and families
  - General groups for families coping with medical diagnoses or cleft/craniofacial-specific groups most often held through a hospital
- Camp programs
  - General camps for patients with a range medical diagnoses or cleft/craniofacial-specific camps that your cleft team can help you identify in your area

Individual/Family Mental Health Services

- Practicing coping strategies
- Building problem solving, social, and communication skills
- Using cognitive restructuring/reframing
- Managing anxiety and relaxation skills
- Building positive self-esteem and self-efficacy
- Reducing depressive symptoms
- Helping with advocacy

The Big Picture

- You as parents and family have the most powerful role in shaping children’s perceptions of themselves and their world
- As difficult as some social situations may be, most children learn how to respond and cope positively
- Resiliency, empathy, and social maturity can develop at a younger age for children with a craniofacial diagnosis from overcoming challenges and their unique experiences with other patients and medical settings
- COVID-19 stressors have contributed to growth in many areas

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School Building Blocks

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Common School Concerns in Cleft and Craniofacial Patients

- Absence due to medical/surgical/orthodontic treatments
- Developmental delays
- Speech and language difficulties
- Fine motor difficulties
- Hearing loss
- Vision loss
- Specific Learning Disabilities
- Executive Functioning difficulties
- Attention Deficit Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorders
- In-school nursing care

Cognitive & Academic Outcomes

- Highly variable but all children with cleft and craniofacial conditions have elevated risks due to their medical status
- School issues are not limited to cognitive functioning, and should include consideration of broader medical, developmental and functional status

School Supports

- Every child with a disability has a legal right to a free and appropriate public education
- Available support services may vary depending on state, district, and school setting
- Quality of support services can vary
- Families should carefully and accurately consider their child’s unique needs when determining plans for schooling

Assessing Your Child's School Performance with Your Team Specialists

- What type of school is your child enrolled in?
- What kind of classroom setting is your child in?
- What are your child's strengths at school?
- What are your child's greatest challenges?
- Are there activities your child struggles to do on their own or like their peers?
- Does your child have an IEP or 504 Plan? What does it include? How often are services received?
- Are you happy with the quality and quantity of supports your child is receiving at school?

Types of Testing

- Psychoeducational
  - Academic functioning: achievement/grade level, need for support
- Neuropsychological
  - Brain/behavior relationships: memory, language, visual perceptual skills, fine motor skills, attention, executive functioning
- Psychological
  - Emotional and behavioral functioning

Individualized Education Program (IEP)

- Individuals with Disabilities Education Act (IDEA) covers school-aged kids with one of 13 disabilities
- Disability must impact educational performance and/or ability to learn and benefit from the general education curriculum, leading to the need for specialized instruction.

Specific Learning Disability
Other Health Impairment
Autism Spectrum Disorder
Emotional Disturbance
Speech or Language Impairment
Visual Impairment (blindness)
Deafness
Hearing Impairment
Deaf-Blindness
Orthopedic Impairment
Intellectual Disability
Traumatic Brain Injury
Multiple Disabilities

Individualized Education Program (IEP)

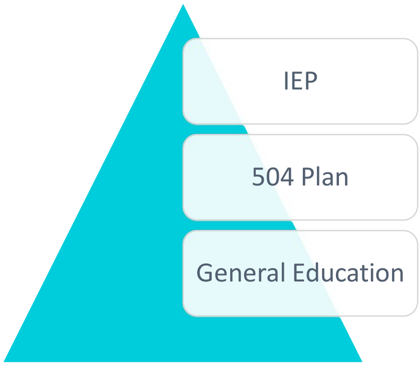
- IEPs have a formalized process that must be followed
- IEP Team must include the following (ideally at all meetings)
  - Child's parent
  - At least one of the child's general education teachers
  - At least one special education teacher
  - School psychologist or other specialist who can interpret test results
  - District representative with authority over special education services
- IEP must outline specific goals, benchmarks, services and personnel

Evaluation
Determination of Eligibility
IEP Writing
IEP Meeting
Implementation
Annual Review
Re-Assessment (3 yrs)

504 Plan Service Agreements

- Section 504 of the Rehabilitation Act of 1973
- Covers individuals who have a physical or mental condition that affects their functioning in a major life activity
  - Walking, seeing, hearing, speaking, breathing, learning, working, self-care, performing manual tasks
- **Goal: placement in a *general education classroom* with services, accommodations, or aids needed to achieve satisfactory academic performance**
- No standard form or template, but is usually a written document
- Usually but not always includes parents
- Suggests but does not require “periodic” evaluation

IEP vs. 504 Plan – What’s the difference?



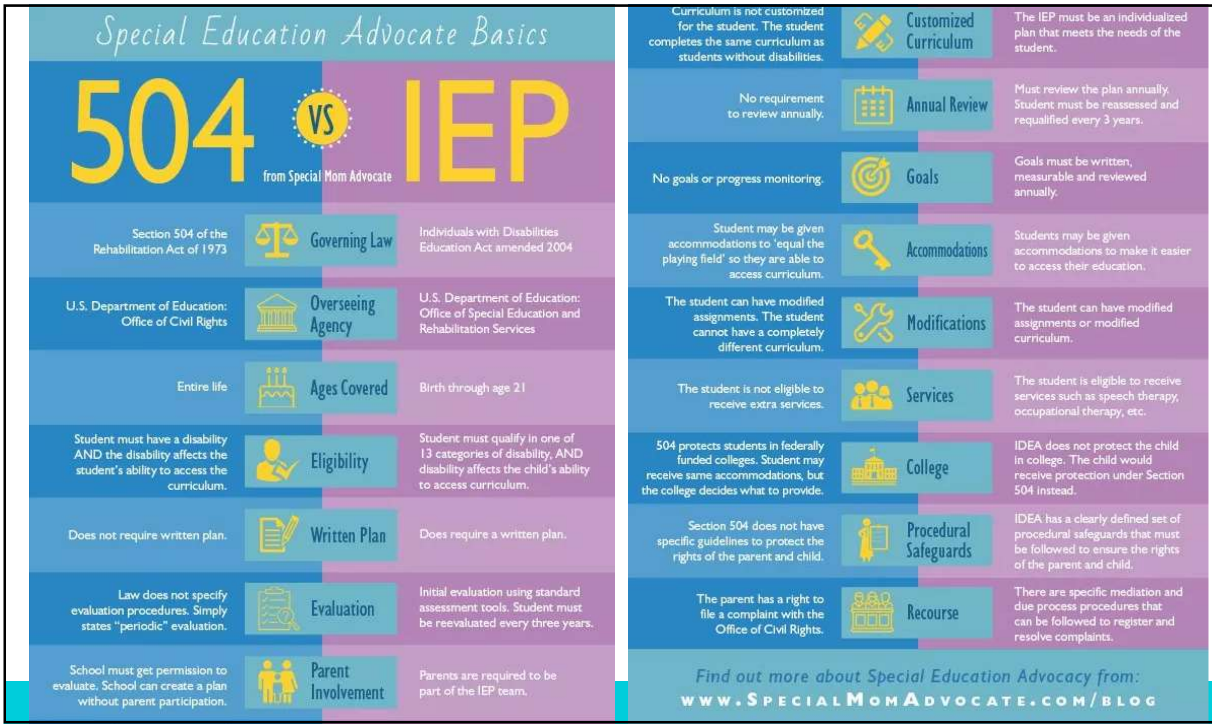
IEP

504 Plan

General Education

- 504 Plan
  - Access to general education
  - Must have a disability that affects *access* to curriculum
  - No formal process or goals
  - All ages (through college and beyond)
  - Modified assignments
  - Student is not eligible for extra services
- IEP
  - Access to special education
  - Must have 1 of 13 designated disabilities that affect access to curriculum
  - Formal process and team, designated goals
  - Age 0-21
  - Modified assignments and/or curriculum
  - Student is eligible for extra services

https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans



Special Education Advocate Basics

from Special Mom Advocate

504	VS	IEP
Section 504 of the Rehabilitation Act of 1973	Governing Law	Individuals with Disabilities Education Act amended 2004
U.S. Department of Education: Office of Civil Rights	Overseeing Agency	U.S. Department of Education: Office of Special Education and Rehabilitation Services
Entire life	Ages Covered	Birth through age 21
Student must have a disability AND the disability affects the student's ability to access the curriculum.	Eligibility	Student must qualify in one of 13 categories of disability, AND disability affects the child's ability to access curriculum.
Does not require written plan.	Written Plan	Does require a written plan.
Law does not specify evaluation procedures. Simply states "periodic" evaluation.	Evaluation	Initial evaluation using standard assessment tools. Student must be reevaluated every three years.
School must get permission to evaluate. School can create a plan without parent participation.	Parent Involvement	Parents are required to be part of the IEP team.
Curriculum is not customized for the student. The student completes the same curriculum as students without disabilities.	Customized Curriculum	The IEP must be an individualized plan that meets the needs of the student.
No requirement to review annually.	Annual Review	Must review the plan annually. Student must be reassessed and requalified every 3 years.
No goals or progress monitoring.	Goals	Goals must be written, measurable and reviewed annually.
Student may be given accommodations to 'equal the playing field' so they are able to access curriculum.	Accommodations	Students may be given accommodations to make it easier to access their education.
The student can have modified assignments. The student cannot have a completely different curriculum.	Modifications	The student can have modified assignments or modified curriculum.
The student is not eligible to receive extra services.	Services	The student is eligible to receive services such as speech therapy, occupational therapy, etc.
504 protects students in federally funded colleges. Student may receive same accommodations, but the college decides what to provide.	College	IDEA does not protect the child in college. The child would receive protection under Section 504 instead.
Section 504 does not have specific guidelines to protect the rights of the parent and child.	Procedural Safeguards	IDEA has a clearly defined set of procedural safeguards that must be followed to ensure the rights of the parent and child.
The parent has a right to file a complaint with the Office of Civil Rights.	Recourse	There are specific mediation and due process procedures that can be followed to register and resolve complaints.

Find out more about Special Education Advocacy from:

WWW.SPECIALMOMADVOCATE.COM/BLOG

Support Services in School Could Include:

- Learning support (pull-out or push-in)
- Reduced/altered workload
- Special education classroom – full time or resource room
- Speech therapy – 1:1 and group
- Hearing support – preferential seating, FM system, written reviews
- Vision support – preferential seating, magnification, large print, audio books
- Physical therapy – gross motor, mobility, accessibility
- Occupational therapy – handwriting, functional independence
- Testing accommodations – oral exams, quiet room, extra time
- Nursing support
- Behavioral support – 1:1, TSS/BSC, daily check-ins, counseling

Talking to Kids About Testing & Services

- Discuss what’s fun and hard about school
- Explain the evaluation process and talk about their team
- Reassure them that it’s not a test they have to study or prepare for
- Emphasize that we all have strengths and weaknesses with skills and learning
- Highlight how testing and support services could help them have a better experience with learning
- Help your child understand their identified issues
- Let them know what to expect from their planned services or accommodations
- Practice answering peers’ questions with your child
- Prepare for a range of reactions

https://www.understood.org/en/learning-attention-issues/understanding-childs-challenges/talking-with-your-child/talking-to-your-child-about-getting-evaluated
https://www.understood.org/en/school-learning/evaluations/should-child-be-evaluated/will-kids-treat-my-child-differently-if-she-gets-services

Requesting School Testing

- **Write a letter** specifying your concerns and request for evaluation
  - Use a template if it’s helpful
  - Be specific and write as much as you need
  - Include your consent for evaluation and request a “Consent to Evaluate” form
- Make sure the letter is received – hand-deliver or send certified mail
- Follow up – give it 1–2 weeks, then follow up by phone or email
  - States vary on how long they have to respond to the request and how long they have until they perform the requested evaluation
- Testing requests could be denied – be persistent!

Advocating for Your Child

Be Informed	Be Patient	Be Persistent
• Know your child's rights to education (see resources on next slide) • Ask questions to understand the evaluation and plans • Seek outside support as needed	• IEP and 504 evaluation and implementation can take many months • Needs can change throughout school years and may require revisions to plans • Not all school personnel understand your child as well as you do!	• It can take multiple requests for evaluation and iterations of a plan to come to fruition • Keep tabs on your kid's services and whether they are being implemented as outlined • Pull in outside support as needed

Resources

American Cleft Palate-Craniofacial Association
https://acpa-cpf.org/acpa-family-services/family-resources/

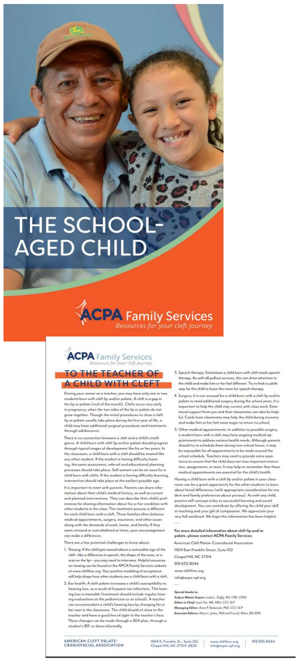
Learning Disabilities Association of America https://ldaamerica.org

International Dyslexia Association https://dyslexiaida.org/

Understood (learning & attention disorders)
https://www.understood.org/

Education Law Center http://www.edlawcenter.org/

U.S. Department of Education
https://www2.ed.gov/about/offices/list/ocr/504faq.html#interrelationship



THE SCHOOL-AGED CHILD

ACPA Family Services
Resources for your cleft journey

ACPA Family Services
TO THE TEACHER OF A CHILD WITH CLEFT

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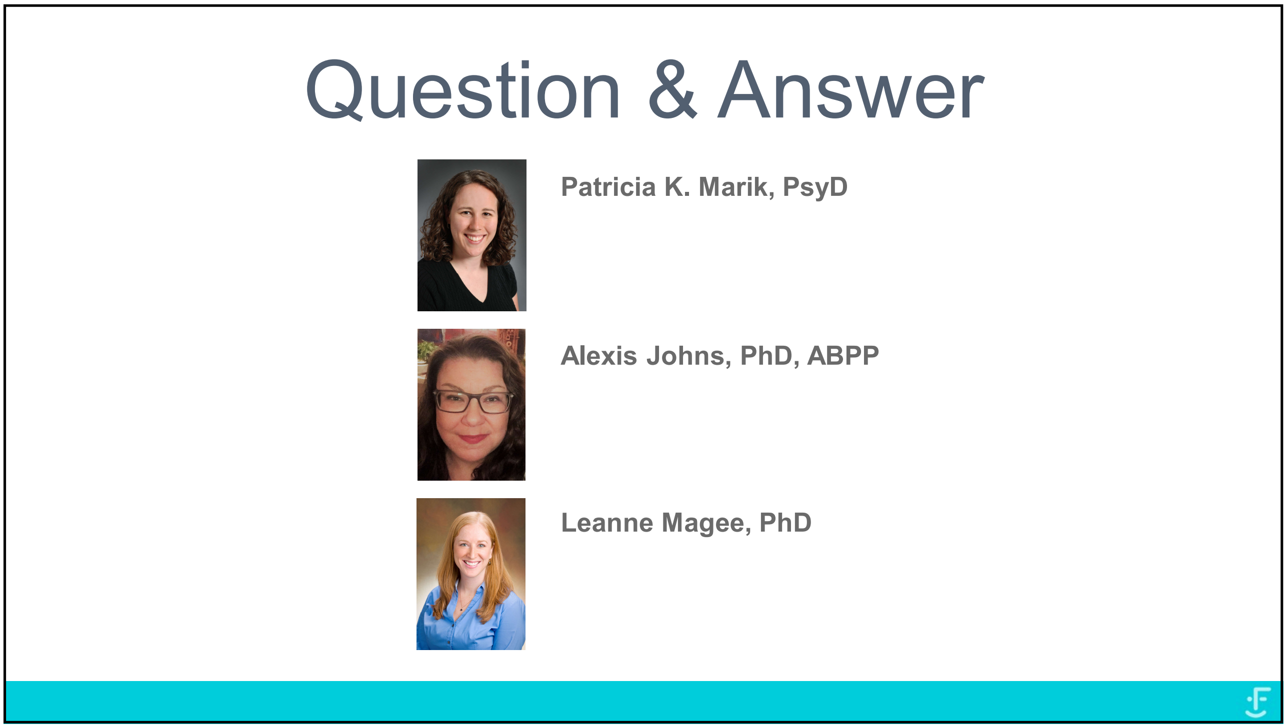

Question & Answer

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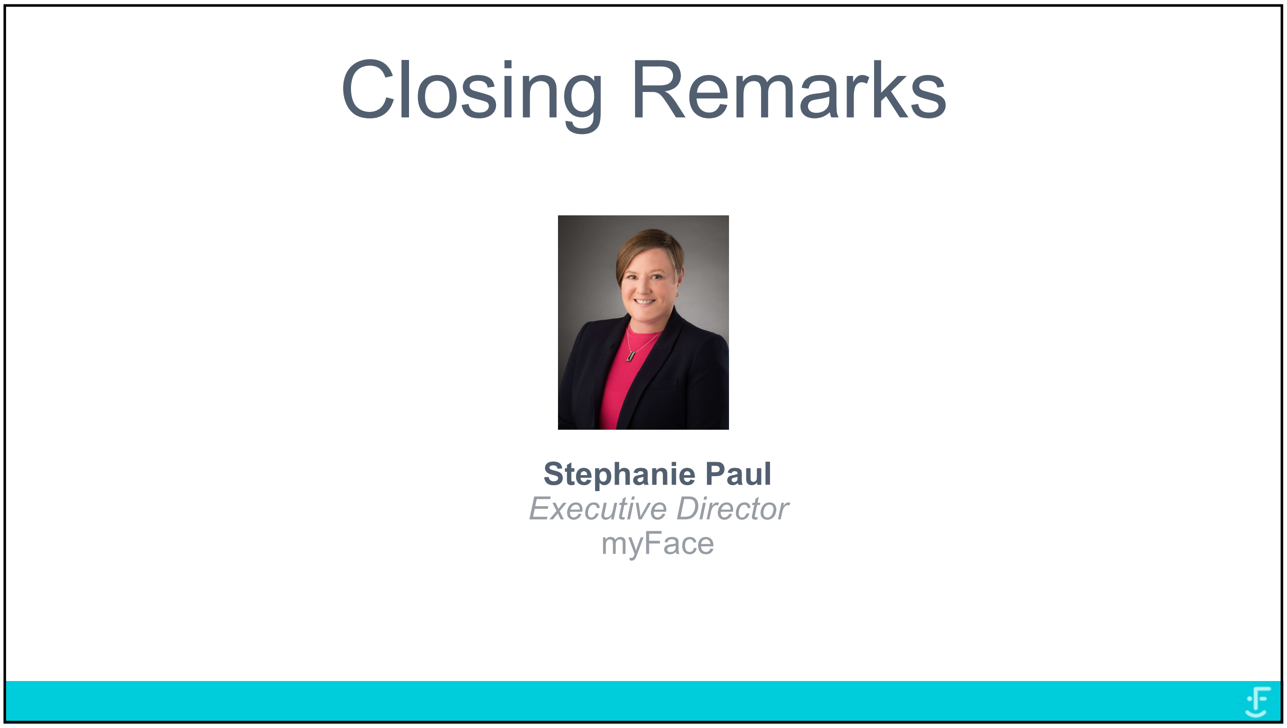
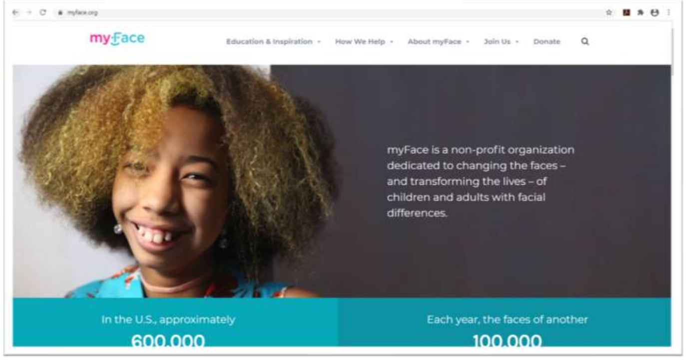


Closing Remarks

Stephanie Paul
Executive Director
myFace

For additional information and resources
visit myFace.org



myface.org

myFace is a non-profit organization dedicated to changing the faces – and transforming the lives – of children and adults with facial differences.

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600,000

Each year, the faces of another
100,000

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