SIBS STICK TOGETHER
Guidelines for today:

- You are all on mute, no video. Go wild!
- Use the question box for questions or comments
- You send questions to me, I will ask them anonymously, or put your name in if you say it is OK
- ahalladay@autismsciencefoundation.org
- Bios are on the ASF page “Sams Sibs Stick Together” under resources
Who is the panel?
Questions for the panel

What would you suggest (parents and clinicians) to families who are now forced together, and the autistic sibling is expressing higher levels of aggression and frustration to the undiagnosed sibling?

For parents of younger children, how do you foster tolerance in the unaffected sibling? What has worked? What should be avoided?

How do you ease the transition of not only siblings staying home during the pandemic but then leaving again when conditions ease?
Questions for the panel

What would you suggest (siblings and clinicians) to families who are now forced together, and the autistic sibling is expressing higher levels of aggression and frustration to the undiagnosed sibling?

Sam: Talk about how the roles in the family are going to have to change. It is about balancing the needs of all family members: parents, and all siblings including those that have ASD. This may mean some time away from the family and a break for siblings, and parents! Children on the spectrum are frustrated, but so is everyone! Finding the balance is important, not every day has to be all about one person.

Erin:
1. Turn to evidence based practices. There is a lack of structure and predictability during the pandemic. Adding a schedule is going to be helpful, for everyone in the family. This should be a visual schedule (or include visuals) so that the person with ASD can understand what is going on. There are assigned roles and responsibilities. Everyone’s schedule should be visible, each family member makes a pact that they can ask each other for help if they need to take that break, and that the roles can be shifted if needed.

2. Try and “predict and prevent” – some things can be triggering for others. Make sure all information that is communicated is concrete and clear so it can be understandable.
Questions for the panel

Erin:
3. Engage in productive activities. You can use regular household activities to promote a routine and learn skills – bathtime, dinner, getting the mail, household duties, dishes, etc.

Kimberly
1. Involve the sibling in the plan and be clear about how to involve the sibling in the plan. Parents/caregivers should let sibling know what they can and should be doing ore responding when a tantrum and meltdown erupts. For example, the parent can instruct them to go to a safe place. Parents can allow siblings to be involved after the crisis has passed. Also express what is expected of them, embed it in the natural part of your day.

Paige
1. Have a plan
2. Make sure everyone knows what their role is
3. The sibling should not feel like it is their responsibility or ”fault” and it is not on them to solve the immediate problem. Everyone takes on their role in the moment.
4. Validate the experiences of everyone in the family, including what that emotional experience is. “I understand this is a bad experience for you...” It is OK to experience whatever you are feeling.
5. Provide unconditional love. Remind them how frustrated you are or hard the situation is, you are in this together as a family.

6. It is so important for us to feel connected to our families and it is so much about quality, rather than quantity of time spent with the family. There should be an understanding that parents may need to spend more time in terms of quality with the diagnosed child, but that does not mean that the quality of the relationship with the undiagnosed sibling is any less.

7. Parents: Try and spend 5 minutes of directed attention for all siblings in active listening. The conversation can be led by the child. When kids can sit with their emotions, it makes them easier to deal with. It feels good to share.

Realize that sometimes these behaviors are the result of not being able to verbally communicate. We can look at the behavior (like aggression) as a communication. What is that behavior saying about their situation? These are less adaptive means of communicating feelings, especially in those in minimally verbal or nonverbal individuals. What is the child with ASD telling us? Need to be very active in listening to behaviors in individuals with ASD. Aggressive behavior might be able to be reshaped to something else.

Nate: These strategies go beyond just aggressive behaviors.
Nate: These strategies go beyond just aggressive behaviors. It can actually be a reduction in activity rather than aggression. Doing activities at home can improve a bunch of behaviors.

Sam: You can reframe so many of daily activities as “therapy” – opening the mail can work towards fine motor function. A game can be created to prepare for a test where you have to stand still and have a lot of sensory input going on. Laundry ”time” can be done as a joint activity and part of a regular schedule.

Kimberly: it does not have to be perfect or 100% of the time, but the more time you reframe everyday activities into
Questions for the panel

For parents of younger children, how do you foster tolerance in the unaffected sibling? What has worked? What should be avoided?

Sam: Tolerance actually came naturally through the lens of the parents attitude. Ben joined into their lives in the same way as any new sibling as a baby would. Spending time with Ben was never forced, it never had to be mandated into the routine. This can create negative feelings. The parents trusted Sam to do things with Ben independently. Her friends were also indoctrinated into her routine as well. There was nothing hidden or secret about Ben. Giving Ben the confidence and making him feel accepted allowed him to be more involved with the family.

Erin: Give everyone a sibling like Sam!
1. Education: sensitivity training, teaching the unaffected sibling about autism, talk about differences in a positive way (including things we like and don’t like) and being different is great. If we start teachings siblings about acceptance, this will build the ability to feel confident and competent about moving forward.
2. Integrating siblings into therapy if possible. Moving them out of the room or trying to shield them from anything in therapy may cause stigma. Allow the sibling to be a part of intervention
3. Reinforce, reward and provide praise to undiagnosed sibling.
4. Reinforce to all children that autism is just a word, need to talk about it early on and what makes kids different and similar. If your kids know it is OK, everybody is going to consider it as normal.

Kimberly:
1. Reframe “tolerance” to “appreciation and acceptance”. Make sure everyone in the family knows that everyone has strengths and things they want to work on.
2. Acknowledge that it is beautiful but it can also be quite hard at the same time.
3. Model this behavior: point out the strengths of the person with ASD, and siblings will also do that.
4. Parents: you are doing a great job! Keep it up! It’s working!

Paige:
1. Rather than building tolerance, reward and acknowledge positive interactions between siblings. Parents: try to catch them in the small successes (doesn’t have to be major, can just be sitting on the couch) and put positive attention on these things. Kids will want to continue to engage in those behaviors.
2. Want to get siblings to a place of appreciation and acceptance in the daily life.
3. Avoid: try to avoid putting blame on the child with ASD. “I can’t help you with this because your sibling needs me...”. This may happen, it’s OK, things happen, but parents to be thinking about the language they use towards both children to avoid the sibling feeling that they are getting less because of a diagnosed sibling.
4. Don’t tell kids how they “should” feel. Validate their feelings whatever they are, including sadness and frustration.
5. Try to connect with all kids. Again, this is hard, there are only so many hours in the day for all people in this family, but try to be present and be in active listening and recognize the small successes.

Kimberly: sibling should be allowed to communicate the good and the bad. Adults should also own their mistakes (whatever was said or done) and bring humility to the situation to show kids that nobody is perfect (even parents!) is critical.

Erin: be prepared for the moments that are not even planned! Recognize in that situation the teaching opportunity or the moments that can be the 5 minutes that make a difference.

Sam: there is no perfect day, situation, the times when we thought we would “plan” a magical moment may never happen, and that’s OK. There may not be a perfect response to every situation for every family. Every family that looks perfect on the outside has their moments.

Nate: He was encouraged to explore his brother’s challenges through his brother’s perspective. Interacting with his brother was not always intrinsically rewarding, and it was hard, but his parents kept encouraging him and shared that his brother was frustrated too. He benefitted from participating in his brother’s therapy and learning from the therapist about his needs.
Questions for the panel

How do you ease the transition of not only siblings staying home during the pandemic but then leaving again when conditions ease?

Kimberly: By utilizing a calendar, visuals, and social stories we can prepare the entire family for the transitions. Including visuals that teach uncertainty such as the “?” can also help teach mental flexibility. We can also reflect on all that we accomplished in this new unprecedented public health crisis. Let’s reflect on what we learned and how we persevered. We can also utilize Zoom to keep in touch with our sibling once they leave again.

Paige: Create a plan and explain that plan to the family. As the circumstance changes, communicate changes in the plan. Anxiety comes from the unknown, so the more everyone in the family knows what to expect (and who is being delegated which roles/responsibilities) the more comfortable everyone will feel. Use social stories, visual supports, narratives during play as needed to communicate around transitions.