

OLDER SIBLINGS WORKSHOP

Age: Over 10 years old

Duration: 4 hours

Schedule

15 minutes: Human Bingo

HUMAN BINGO

Supplies Needed:

- Copies of the BINGO sheet (at end of document) for each participant
- Writing utensil for each participant (a choice of a colored marker has always been popular)
- Small token reward as participants finish.
 - We would recommend against sugared rewards
 - Consider, instead, stickers, squish balls, light-up rings, etc.

Lessons learned:

- Participants will get to know each other, particularly names
- Participants will foster personal connections that can set the stage for more sharing later in the workshop

This is a great activity to have brothers and sisters do as they arrive. If you have very young participants, who don't read or write yet, you may want to provide some other games available for them to entertain themselves with.

For this activity, give brothers and sisters a “human bingo board” that has different facts people may have about themselves. Brothers and sisters can use this board and its questions to ask people things about themselves and get to know one another! When someone finds another person who has that fact true for themselves, they write their name on your paper, in that question’s square. You can give this to brothers and sisters as they’re coming in and play with everyone until you’re ready to begin your Workshop. Whoever gets all the blanks filled gets a prize!

For example, here are some human bingo questions:

“Has blue eyes” “Likes to sing in the shower” “Likes Italian food” “Likes baseball” “Can whistle”

As a participant, if I found someone who had blue eyes, they would sign their name on that square on my bingo board. Once I have a *different* name for each question, I win a prize!

5 minutes: Welcome

- Go over bathroom locations, confidentiality, respecting one another

20 minutes: Down syndrome Jeopardy

DOWN SYNDROME JEOPARDY

Supplies Needed:

- Jeopardy board (attached to end of document)
- Facilitator’s copy of questions and answers

Lessons learned:

- Participants will learn important facts about Down syndrome in a fun, memorable way.

This a great activity to use with brothers and sisters to teach them some good facts and FAQ's about Down syndrome. You may want to adjust the questions for the age of the participants. If your brothers and sisters are too young for this activity, see the activity titled "Similar and Different: Sibling Drawings." Use the topics covered in this game as a jumping off point for further discussion about what Down syndrome actually is. Make sure to revisit topics brought up in Jeopardy during the Question Box session.

For more information about the facts and science of Down syndrome, check out Dr. Brian Skotko's and Sue Levine's book, *Fasten your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*, Chapter 1, Gearing Up to Go: getting the facts about Down syndrome!

10 minutes: BREAK

45 minutes: Advocacy/Policy Scenarios

Supplies Needed:

- Copies of the scenarios for participants (attached to end of document)
- A writing utensil in case participants want to take notes

Age group: 13 and up

Lessons Learned:

- Empathy for other siblings' experiences
- Empathy for parents' experiences
- Problem-solving skills

At the bottom of this page, you will find a variety of advocacy and policy scenarios that display a brother or sister in a different, perhaps stressful, situation. These are situations that may often arise for our brothers and sisters. Having the opportunity to think through them here and develop some strategies and opinions will help our brothers and sisters when they get put in these situations in real life.

Some of the scenarios ask the brother or sister to put themselves in the position of the brother/sister in the scenario. For example, "You are walking through Target when all of a sudden, your sister, who has Down syndrome, sits down in the middle of the store. You're so embarrassed! What can you do next?" The brothers and sisters participating would discuss what next steps the sibling could take in that situation.

Other situations ask the brother or sister participant to put themselves in the position of the parent of someone with and without Down syndrome. This will help the brothers and sisters to gain an understanding for what it's like to be the parent of someone with Down syndrome. For example, "Your daughter Maria told you that she's really embarrassed when her sister, Nellie, who has Down syndrome, always has her tongue sticking out. What would you tell Maria?" The brothers and sisters participating would discuss the next steps a parent could take here.

These scenarios will give the facilitator to establish three things:

1. Facts of the situation and Down syndrome
2. Validation and listening of feelings
3. Problem-solving strategies for brothers and sisters,

all of which are vitally important when discussing these situations.

The scenarios below are organized based on topic. Groups may find it more efficient to talk about these scenarios instead of everyone taking time to write a response. Use these scenarios as opportunities to talk more in depth about some of the topics that will be covered in the various situations.

15 minutes: Sensitivity Game: Spelling Test

SPELLING TEST

Supplies Needed:

- Paper
- Spelling words for leader
- Writing utensil

Lessons learned:

- Participants will gain empathy for their siblings and others, especially in an academic context.

In this game, leaders should have a list of spelling words that they ask participants to write down on their paper. Have participants number their papers 1-10. Then, instead of saying the spelling word, sign it! Talk about

how confused they feel with the words presented in that fashion. Discuss when their sibling might feel this way in a school setting.

30 minutes: MEAL BREAK

- Depending on the time of your 4-hour workshop, make sure to provide snacks, water or lunch

20 minutes: Things Parents/Others should know

THINGS PARENTS/OTHERS SHOULD KNOW

Supplies Needed:

- Paper
- Writing utensil
- If you want to film, phone or other camera/video camera

Lessons learned:

- Participants will be given the opportunity to talk about their experiences and learn from one another and the facilitator about these topics, as well as communicate some of their needs to their parents, friends, etc.

Ask brothers and sisters to write and/or record (in some cases, we have filmed the siblings) some things they think their parents should know about being the brother or sister of someone with Down syndrome (may touch on some things under Topics). Additionally or alternatively, they might write about something that they think others should know about Down syndrome in general or specifically their sibling.

This will give brothers and sisters the opportunity to convey both the medical/biological facts of Down syndrome, as well as expressing their

personal and practical knowledge that comes from being a sibling and viewing this person with Down syndrome as more than a list of facts and features as defined by their diagnosis.

After everyone has had a chance to work on their own—or in pairs—reassemble as a group to share thoughts. You can use the responses to draw out validations and responses from other participants.

15 minutes: How do you cope?

HOW DO YOU COPE

Supplies Needed:

- Small rocks, pebbles
- Paper
- Index cards--enough for each participant
- Markers
- Paint

Lessons learned:

- Participants will find a new way of expressing and understanding their feelings about their sibling.
- Participants learn some practical skills to help deal with some stressful situations that they can take back home with themselves.

For this activity, have participants first begin by talking about some stressful or uncomfortable situations. Talk about the emotions that these situations evoke. Then, talk about how the brothers and sisters cope with these situations. They will all likely have different ways of coping, and that is great! Everyone can have the opportunity to learn from one another.

Have the participants then paint the rocks and write or draw on them something that signifies to them their coping strategy. They can take the rocks/pebbles home or to school or wherever will serve them best, to help them remember that others have similar experiences, as well as some good strategies to use whenever they're in these situations! If the participants are older and don't want to paint the rocks, they can just write some strategies or doodle some ideas/pictures on some paper or index cards.

10 minutes: Sensitivity Game: Helping siblings with difficult tasks

HELPING WITH DIFFICULT TASKS

Supplies Needed:

- Paper
- Writing utensil

Lessons learned:

- Participants will gain empathy and understanding for their sibling
- Participants will be able to learn practical things they can do to help their sibling
- Participants will gain information about Down syndrome and how it affects their sibling

In this game, brothers and sisters should brainstorm ideas of how to best help their sibling through what can sometimes be some very difficult situations, as well as think about what will help your sibling learn more easily. Here is some advice on strategies that is also outlined in our Topics section on this site.

- Being shown what to do first
- Using a hand-over-hand technique to complete a task like handwriting or brushing teeth
- Having a peer buddy in the classroom
- Getting extra help from the teacher
- Smaller class sizes, etc.

This will help brothers and sisters think through situations that will give them practical skills to apply with their siblings to guide them through some of what are usually frustrating tasks.

10 minutes: BREAK

10 minutes: Sibling Slam Book

SIBLING SLAM BOOK

Supplies Needed:

- *The Sibling Slam Book* by Don Meyer

Lessons learned:

- Participants discuss common situations and emotions experienced by other brothers and sisters of people with Down syndrome, as well as other disabilities.

- Participants will have the opportunity to develop practical problem-solving skills to address these situations in the book that will likely appear in their lives, too.

Participants can take turns passing around *The Sibling Slam Book* by Don Meyer, flipping to a random page and answering the question or addressing the situation on that page.

15 minutes: Question Box

QUESTION BOX

Supplies Needed:

- Index cards
- Markers/pens
- Shoe box

Lessons learned:

- Participants will have the freedom to ask questions about Down syndrome and their sibling, specifically, that they may not normally ask
- Participants will get accurate answers to their questions about Down syndrome, learning good facts
- Participants will benefit from the discussion and requisite growth around a particular topic

The Question Box is a great activity that gives brothers and sisters the opportunity to anonymously write any questions they have about their sibling on an index card and drop it into a shoe box or bag positioned in the room. You may want to start with a time to write some questions down at

the beginning of the Workshop and then follow up with some designated time throughout the rest of the Workshop. Brothers and sisters should also know that they can write questions throughout the Workshop, outside of the designated times, as well. It will be important to leave the index cards and pencils out for participants to use through the Workshop. At other times throughout the Workshop, assemble the brothers and sisters into a circle (different circles for each age group). Ask one of the participants to pull a question and read it out loud, and then you can ask for some advice from the other participants. Oftentimes, siblings can help each other and answer their own questions! Other times, you might need to jump in and offer some direction or reflections. Use these questions as opportunities to talk about some larger topics that are important to brothers and sisters. Make sure you create a safe environment so that brothers and sisters feel safe to share their thoughts and ask any questions there that they may have.

15 minutes: Closing Remarks

- Share with them *Benefits of Having a Sibling with Down Syndrome*
- Have them come up with their own list of benefits!
- Go around the room and have participants share their favorite activity or topic

BENEFITS OF HAVING A SIBLING WITH DOWN SYNDROME

There is a long list of all the benefits of having a sibling with Down syndrome. Your sibling will show you things about the world and your life that you never would have learned except through them. We are a special group of people; I can promise you that. Things can be tough; there's no

doubt about it. But your sibling will provide you with unconditional love and teachings about yourself and others. Siblings of people with Down syndrome listed the following things as just a few of the benefits they've gotten from being the sibling of someone with Down syndrome.

KEEP IN MIND...

1. Acknowledge the range of feelings that siblings may bring to the workshop.
2. Say what they feel is common—others experience that, too.
3. Give them practical things to do to remedy the situation.

RESOURCES TO CHECK OUT

1. Read up on different Topics to prepare for any questions that may arise!
2. Look under Activities to download worksheets and explore different games.
3. Check out Dr. Skotko & Sue Levine's book *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters* for more helpful information!

HUMAN BINGO

Has blue eyes	Likes to sing in the shower	Was born in September	Likes Italian food	Likes baseball
Can name a U.S. state that begins with "C"	Can curl his/her tongue	Reads the newspaper in the morning	Has gone fishing	Prefers vanilla to chocolate
Likes winter better than summer	Likes bananas	Has a sister or brother with Down syndrome	Can whistle	Likes pepperoni pizza
Likes to watch scary movies	Likes to swim	Can wink	Is wearing brown shoes	Went to zoo last year
Is the oldest child in the family	Has a cat	Has visited another country	Plays soccer	Can count to ten in another language

Down Syndrome Jeopardy

Science

100 The number of chromosomes in every cell of a person with trisomy 21 (47)

200 It is this numbered chromosome that is often tripled in someone with Down syndrome (21)

300 The name of this genetic test can be used to count the number of chromosomes after a child is born (karyotype)

400 This type of Down syndrome can be inherited (translocation Down syndrome)

500 Research into this condition is helping scientists learn more about memory formation in persons with Down syndrome (Alzheimer's disease)

Celebrities

100 The first name of the person who named Down syndrome (John)

200 She was an actress on Glee and frequently advocates for people with Down syndrome (Lauren Potter—real name; Becky Jackson—character on Glee)

300 The name of the children's television series that first had an actor with Down syndrome (Sesame Street)

400 It was this U.S. President who first formed a committee on cognitive disabilities (Kennedy)

500 She was the first person with Down syndrome to swim the English channel (Karen Gaffney)

Education

100 Its initials are IEP (Individualized Education Plan)

200 This term means that people with disabilities are educated alongside with students who do not have disabilities (inclusion or mainstreaming)

300 People with disabilities have a right to a public education through this age (21)

400 This professional, abbreviated OT, oftentimes helps people with Down syndrome learn fine motor skills (occupational therapist)

500 This educational bill ensures that students with disabilities are receiving an appropriate education (IDEA)

Organizations 100 This athletic organization was founded by Eunice Kennedy Shriver (Special Olympics)

200 This national DS parent organization puts on national conferences about Down syndrome for family members (NDSC)

300 This national DS parent organization organizes Buddy Walks (NDSS)

400 This program, established in school systems, befriends people with disabilities and students without disabilities (Best Buddies)

500 This national DS organization helps fund research efforts about Down syndrome (LuMind Foundation)

“Down” Syndrome

100 When doing this, one must be careful not to catch a computer virus (download)

200 A common nickname for Australia (down under)

300 This fabric softener is often used to fluff towels (Downy)

400 This popular TV series, featuring the fictional Crawley Family, took place in 1920's England (Downton Abbey)

500 He plays a super hero that is part of the Marvels Comics (Robert Downey Jr.)

Advocacy & Policy Scenarios

Medical Scenarios

You were invited to your friend’s house for a sleepover on Friday, but you’re kind of nervous about going because some of the other people invited always ask you about your brother, Elijah, who has Down syndrome. One question they recently asked you was if you would have a kid with Down syndrome when you get older. How could you respond?

- To answer the question about heritability of Down syndrome for the sibling, refer to the “Topics” section of this site that discusses this very question!

Pretend you’re the parent of two children: one has Down syndrome and one does not: While shopping in the grocery store with your younger son, Alex, you ask him if there was anything about his older brother, Neal, who has Down syndrome, that bothers him. He asks, “Will he always stick out his tongue?” How would you approach the situation?

- Sometimes people with Down syndrome will have protruding tongues due to their sometimes having larger tongues or smaller upper jaws, as well as the low muscle tone necessary to control the tongue. As your sibling gets older and completes more speech and physical therapy, they will gain better control over their tongue. Maybe you should also talk about why this makes the brother or sister uncomfortable—are they embarrassed? It’s okay to be embarrassed; discuss how to deal with others staring by checking out the “Topics” section of this site.

Today in science class you learned that people with Down syndrome have many medical complications and can get Alzheimer’s when they get older. You’re now worried about how long your sister with Down syndrome will live. What can you do about your fears?

- People with Down syndrome are at an increased risk of developing Alzheimer’s as they get older. You can make sure that your sibling is seeing a trusted physician regularly to maintain their health and address any concerns you, your sibling, and family have.

*For more information on this topic, check out Dr. Brian Sktoko's and Sue Levine's book, **Fasten your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters, Chapter 1: Gearing Up to Go: getting the facts about Down syndrome, page 14!***

Education Scenarios

Your younger brother, James, has to repeat the first grade. James has Down syndrome, but you're still not sure as to why he has to repeat a grade because you never had to do that. What can you do to get some answers to your questions?

- For more information on education, check out Dr. Brian Sktoko's and Sue Levine's book, *Fasten your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters, Chapter 2, Road Test: how people with Down syndrome learn!*
- Repeating grades is not uncommon for people with Down syndrome. Explaining Down syndrome in the context of this situation and reiterating that Jami is very capable of learning, but sometimes it takes her a little bit longer, will be very helpful for Mariah to understand Jami's educational needs and potential!

You may notice that your younger sister with Down syndrome only sits with two other kids who have various disabilities at lunchtime. You also notice that no one really seems to want to be their friends. You're a big advocate for inclusion, so you want to make sure your sister and her friends feel included. What can you do in this situation?

- Sometimes people with Down syndrome would rather sit with other people who have disabilities because they may be around them more in classes or because they understand each other better because they're more similar—ask Naveah what she thinks! Is she happy sitting there? Does she want to sit somewhere else? The important thing is that Naveah has the option and opportunity to sit wherever she likes. If you feel like other students aren't welcoming or inclusive of Naveah and her friends, you may want to talk to some teachers or the principal about how students with disabilities are viewed at school. You could even start programs like Spread the Word to End the Word, Best Buddies, or Special Olympics Unified Sports to increase awareness and attitudes of respect and inclusion at school.

Imagine you're a parent of two sons, one of whom has Down syndrome and the other does not: Miguel, your son with Down syndrome, has just started twelfth grade. Your younger son, Juan, who is a freshman, wants to know if Miguel is graduating this year. How do you respond?

- You can tell Juan that people with Down syndrome and other intellectual disabilities are eligible to go to high school through their 21st birthday. You can include Juan and Miguel in family discussions about whether or not Miguel should continue in school for some more time or if he should graduate and pursue college or a job.

Social Scenarios

You're getting ready to leave for college and move away from home for the first time. As you're packing your things, you begin to wonder about your brother, who has Down syndrome, and what his future will be like. Will he go to college? What will he do after high school? Where will he live? What can you do to get some answers to your questions?

- All of the topics in these questions are covered in the "Topics" section of this site!
- People with Down syndrome live in a lot of different settings! Some prefer to stay home with their parents, live with other family members, live with roommates in a group home, or live by themselves. Talk with your sibling and family about their goals so you know how to help your sibling reach their goals

This summer you're just about to begin your very first summer job! You will be working as a lifeguard—your dream summer job. But then you begin to wonder if your sister, Jackie, who has Down syndrome, will ever have a cool job of her own one day that she's able to be excited about. What can you do to discuss your concerns?

- People with Down syndrome can get all sorts of really cool jobs! Sometimes it can be difficult for people with Down syndrome to find a job because people don't always understand everything they're capable of, but your sibling can show them quickly all they have to offer! There are some great employment resources through information on Employment First states and NDSC

Imagine you're the parent of two sons, one of whom has Down syndrome and the other does not: Your seventh-grade son, Tim, comes home from school quite upset about getting a B+ on his recent biology exam. Tim prides himself on always getting A's. You begin to wonder if Tim is trying to overcompensate in his pursuit of perfection, for his brother with Down syndrome. How would you approach this with Tim?!

- Approach the situation with Tim carefully. Sometimes brothers and sisters may not even realize their pressure for perfection, so the best thing you can do as a parent is to reassure Tim that he is enough and perfect in your eyes, no matter if he gets an A or a B. Remind him of all the great things he does and his worth beyond those accomplishments.

For more scenarios, check out the Activities section of the website!