

# WORKSHOP FOR BROTHERS AND SISTERS OF THOSE WITH AN X OR Y VARIATION

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EMORY

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# INTRODUCE OURSELVES AND SAFE SPACE AGREEMENT



# INTRODUCTION

- X and Y chromosome variations are characterized by a wide variation in symptoms and severity among individuals
  - Behavioral challenges
  - Social difficulties
  - Cognitive impairment
  - Communication deficits
  - Learning difficulties
  - Autism spectrum disorder
  - ADHD/ADD

# INTRODUCTION

- Medical considerations
  - Medication management
  - Clinic visits
  - Hospitalizations
- Impacts the level of independence of the individual
- Affect the sibling
- Long-term implications
  - Ability to finish school, settle into careers, and live independently as adults

# OLDER SIBLING

- Adapting to change of new sibling
- New sibling has increased needs
- Attention of parents may be diverted
- Previous life before sibling now changed



## YOUNGER SIBLING

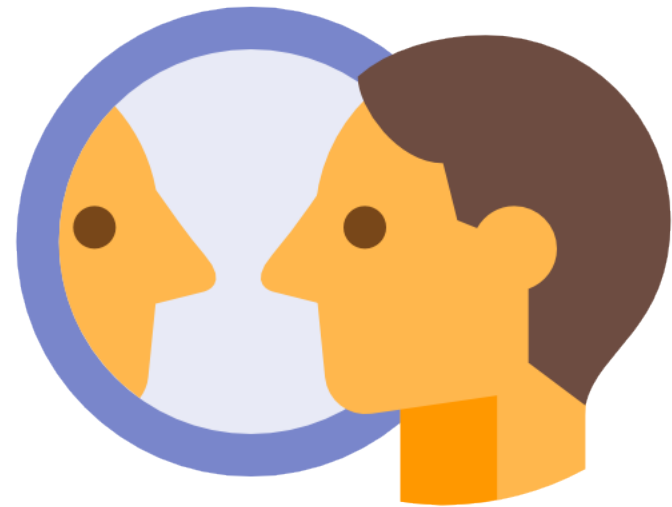


- All they've known is living with their older sibling with x and y variation
- “Growing up in the shadow of x and y variation”
- Fear of increased parental expectations



# HOW DO SIBLINGS FEEL?

- Identity
  - Other than the sibling of an individual of x and y variation
  - Role confusion
  - Had to grow up faster



# HOW DO SIBLINGS FEEL

- Frustrated and angry
  - May perceive sibling with x and y variation to have less responsibility and accountability
  - Extra responsibilities
  - “Held to a higher standard”





# HOW DO SIBLINGS FEEL?

- Jealousy
  - Sibling is getting the attention
  - Perceived less attention paid to them by parents
- Guilt
  - As they meet milestones, leave home, move out knowing the other is not
  - Guilt over their emotions, including jealousy
  - Guilt later in life as they look back on their emotions and actions



## HOW DO SIBLINGS FEEL?



- Pressure or anxiety
  - Perceived increased scrutiny
  - “Set a good example”
  - Reports of feeling like a 3<sup>rd</sup> parent
  - What does the future have in store?

# HOW DO SIBLINGS FEEL?

- Difficulty sharing their feelings
  - Tend to listen more than talk
  - Fear of judgement
  - Saying aloud confirms what is happening or that their feelings are real
  - Guilt
  - Fear of disappointment
  - Disregarded when providing input or suggestions



## IMPACT ON SIBLINGS

- Throughout childhood, but intensified during teenage or transition years
- Stress
  - Stress is how the brain and body respond to any demand
  - Increased in siblings of individuals with chronic illness and developmental disabilities (e.g., x and y variations)
  - Effect physical and mental health

## COMMON EFFECTS OF STRESS

On your body	On your mood	On your behavior
Headache	Anxiety	Overeating or undereating
Muscle tension or pain	Restlessness	Angry outbursts
Chest pain	Lack of motivation or focus	Drug or alcohol misuse
Fatigue	Feeling overwhelmed	Tobacco use
Change in sex drive	Irritability or anger	Social Withdrawal
Stomach upset	Sadness or depression	Exercising less often
Sleep problems		

## IMPACT ON SIBLINGS

- Physical health
  - High blood pressure
  - Heart disease
  - Obesity
  - Diabetes





## IMPORTANT FOR SIBLINGS

- Speak up
  - Advocate on your own behalf
- Seek support
- Take care of your self
  - Mental health
  - Physical health
- Consideration for Transition
  - Participating in transition discussions
  - You always have a choice
  - Planning
  - Optimal discussions starting at 14

## IMPORTANT FOR PARENTS

- Create an opportunity for siblings to focus on their feelings
- Provide an opportunity for siblings to discuss reactions to their sibling's diagnosis
- Beginning at age 6 provide information about their sibling's diagnosis
- Discuss how to explain their sibling's behavior/diagnosis to others



## SIBLINGS-CELEBRATE YOURSELF

- Siblings of x and y variation are more likely:
  - To accept differences in other people
  - To be a loyal friend and partner
  - To be smarter and more mature than kids their age
  - To adapt to different situations

## WHAT SIBLINGS HAD TO SAY

**Try to spin  
everything to  
a positive**

**Don't dwell  
on any  
short  
comings**

**They can really  
make your life  
better rather  
than be a burden**

**They drive us  
crazy but we cant  
live without them!!**

**Cherish  
them!!**

# SUPPORT



- Social media support groups
- Other online support groups
- Teletherapy
- Traditional in-person support groups

## SIBLING SUPPORT

- <http://www.theotherkid.com>
  - Resources for siblings of children with disabilities
- <https://www.siblingsupport.org>
  - Siblings of of people with special health, developmental, and mental health concerns.
- <https://genetic.org/im-adult-looking-answers/support-groups/>
  - AxyS- international, national, local, online, condition specific groups



# SUMMARY

- Having a sibling with x and y variations can be accompanied with certain challenges
- BUT consider all the advantages they give you
  - Patience
  - Empathy
  - Friendship
  - Love
  - Compassion
  - Acceptance



# SUMMARY

- You are **not** alone
- Seek out support groups
- Allow your voice to be heard
- Share with others
- In return, support others
- Consider participating in planning
- Take care of yourself
- Everyone feels stressed from time to time





THANK YOU

