

Suspecting Autism?
Pursuing a diagnosis?
Just got a diagnosis?

Autism Resources

WA state

December 2024

Sara Goegebuier
SLP-A

Dear Parent,

Whether you are considering, pursuing, or have already received a diagnosis, these resources are here to help you increase your understanding of Autism Spectrum Disorder (ASD) and your child's inner world.

This can be an overwhelming process. Please understand that even with a diagnosis, your child will remain the same precious individual kid. Please take the time to paint a little picture of your child in your head and hold it close as you learn more about this world of ASD. As a clinician, I hope you keep in mind three things:

You are doing a great job. An Autism diagnosis does not make you a bad parent. You are doing all the right things in trying to understand your child's world and help them to navigate it.

Not everything will make sense right now and that's ok. You are not alone. There are a variety of resources for you to connect with other parents and Autism communities.

Once you've met one person with Autism, you've met one person with Autism. Autism presents so uniquely in each person. Not every therapy or idea that someone else tries with their kid will work for your kid, even the most well-meaning suggestion by another parent or family member.

Most sincerely,


Sara Goebuer

Speech Language Therapy Assistant
Speech for Success LLC



Strengths

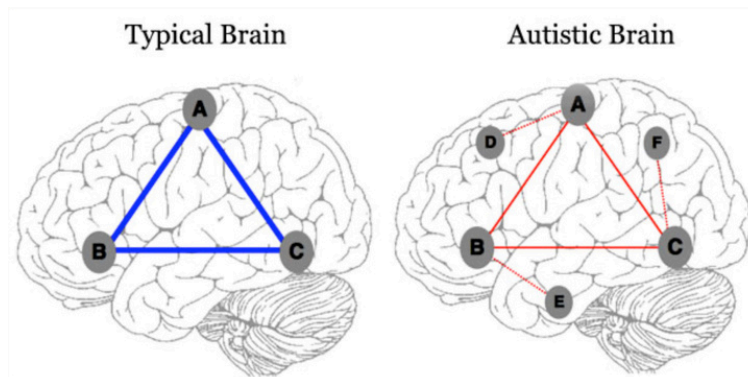
Each of our kids with ASD have wonderful gifts, passions and strengths. Take a moment to paint a picture of your child in your mind.

What are their loves? Passions? Fears? Are they more organized? Creative? Cautious? Risk-takers?



What is Autism?

Autism Spectrum Disorder, commonly known as ASD, is a **difference in how the brain develops connections**. Though scans can't diagnose anyone, you can see the differences on a brain scan. Paths that light up for processing information will be different than a typical person. How this impacts someone's daily life varies widely by person.



A person with Autism may experience...

- Difficulties with communicating or social interaction
- Special interests or fixations
- Repetitive movements, known as stimming
- Difficulties with sounds, lights, textures, motion and other sensations
- Brain-Body disconnect (Apraxia, Dyspraxia) - a person's body doesn't obey their thoughts



What Causes Autism?



The cause of Autism is unknown. There is some correlation to genetics and environmental factors like prematurity. Extensive medical studies conclude there is no correlation between Autism and vaccines. The current rise in diagnoses are because the ASD diagnosis requirements expanded in 2013 to include a wide variety of developmental conditions.

There is nothing that you did as the parent to cause Autism. Your child was born with Autism the same way a child is born with red hair or brown eyes.

Let's take a moment.

Call to mind the picture you painted of your precious child.

Your child will develop at their own pace.
There are reasons for the behaviors.
There are resources available for you!



TERMS AND DEFINITIONS

ASD diagnosis has recently expanded to include a variety of developmental conditions.. Many terms are used to self-identify with a particular range of experience on the Spectrum. This short list is meant to give the reader an idea about how people use terminology surrounding Autism as of November 2024.

SELF-IDENTIFYING TERMS

The Spectrum

A descriptive term for the wide range of symptoms and life impact in Autism

Neurodivergent

Someone whose brain processes differently from the majority of the population

Neurotypical

Someone whose brain processes like the majority of the population

On the Spectrum/Autistic/Have Autism

Terms people on the spectrum may commonly use to describe themselves

AudiHD

A self-descriptor for someone who has an ADHD and ASD diagnosis and/or resonates with the AudiHD group

Nonspeaking/Nonspeaker

Someone who does not use speech to communicate their thoughts

AAC user

Someone who uses Augmentative and Alternative Communication (AAC) via letter board, smart tablet, switch, picture cards, or other means.

Masking

To hide or internalize Autistic behaviors to blend in. Masking has negative mental health effects over time, and can lead to shutdown or meltdown.



COMMON CO-OCCURRING CONDITIONS

Autistic burnout

Extended periods masking or overwhelm without respite resulting in shutdown or meltdown.

Apraxia, dyspraxia

The body does not obey the brain's motor plan, so the person cannot make purposeful or precise movements, often including those needed for speech.

PDA

Pathological Demand Avoidance - shutdown or meltdown when asked to do something

ARFID

Avoidant Restrictive Food Intake Disorder - avoiding or restricting food intake due to sensory sensitivity, trauma, or lack of interest in eating food

Autoimmune disease

The body attacks itself due to an overactive immune system. Examples include Celiac's Disease, Lupus, and Crohn's disease.

Autonomic disorders

Disorder of the involuntary nervous system (regulates breathing, heartbeat, body temp, etc). They can be caused by autoimmune damage to the nervous system. Examples include POTS and Ehler's Danlos Syndrome (EDS).

Autistic Meltdown

An involuntary loss of control over oneself due to overload or overwhelm. It may look like a tantrum, but is involuntary and requires calm response without punishment.



UPDATED TERMS

Terminology for Autism has changed through the years and will continue to change. Medical diagnosis of Autism was fairly narrow, but now has merged to include a spectrum of developmental disabilities and conditions. This is a list of descriptive terms that have officially changed or been accepted into general use (2013-2024).

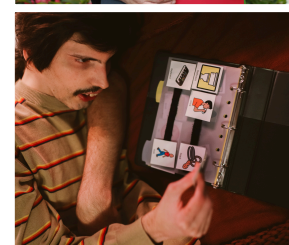
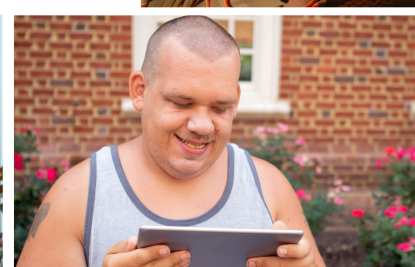
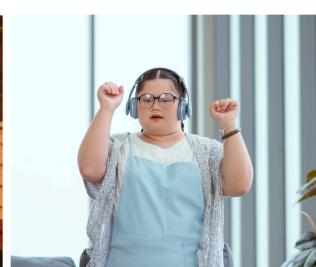
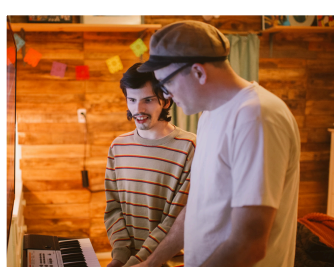
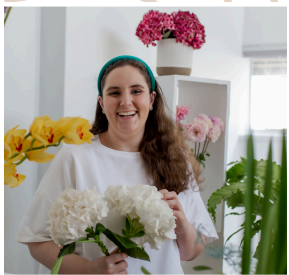
Outdated	Current
“Mild, moderate, severe”	Needing _____ supports
“low functioning, high functioning”	Having _____ support needs
“Nonverbal”	Nonspeaking

Why the shift?

Current terminology is accepted in professional settings and Autistic communities as being more descriptively factual without derogatory connotation.

“Functioning” is no longer in use because it is scientifically inaccurate and stigmatizing. Current terminology indicates that people with sensory-motor difficulties are fully present, simply need different **supports** (social, sensory, etc) to be successful. DSM-5 diagnostic terminology uses three levels to describe ranges of **supports**. The term focuses on the strengths of each person while accurately describing each person’s challenges.

“Nonverbal” implies lack of communication. Yet **Nonspeakers** often use other means to communicate like sign language or Alternative and Augmentative Communication (AAC). **Nonspeaking** favors a more accurate description.



What can I do right now?

Consult an OT for services to help with stimming and sensory regulation. Consult a speech therapist to help with language.

Stimming: swinging, rocking, mouthing, pushing, hand motions.

- DON'T stop the movement. Stimming is a way to calm yourself down when the brain doesn't process sensation typically. It's like putting in earplugs for a screeching siren.
- Provide your child with ways to get the sensation out. If they are mouthy, buy a "chewy tube" or other chew toy. If they don't stop moving, try a yoga ball, swing or rocking chair.



Covering ears or eyes, avoiding textures, tantrums, etc.

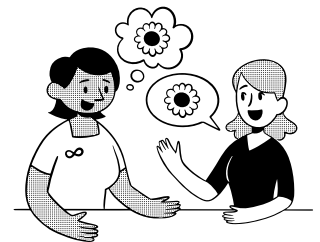
- Provide a picture schedule with expectations. EX: we are going to the store, it will be loud with bright lights.
- For loud noises, consider ear muffs. For bright lights, provide hoods or soft, comforting objects.



Check out [Ella Wu's OT blog: OTEllaBella](#) for info on stimming and sensory avoiding.

Repeating (echolalia, gestalt language processing)

- Recognize that your child is attempting to communicate.
- Repeat language back to them to show you are listening.
- Model phrases from their perspective that begin with words like "let's" "gotta..." DON'T make them repeat you or "say ___".
- Narrate from your child's perspective " I'm feeling mad. I wanna play. Let's go!"



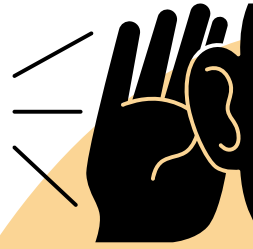
Check out [MeaningfulSpeech.com](#) for more info on repeating, known as echolalia.



Autism and Competence

Cognition and language testing require motor-skill based response (pointing, talking, moving) which can be problematic if a person has sensory-motor impairments due to Autism. This can result in mistaken conclusions that the person cannot learn or understand, when the opposite is true.

Someone can understand everything around them but their brain doesn't allow their body to obey them in response. Internal thoughts are hidden without communication.



We must presume competence!



What is “presuming competence?”

Treating someone respectfully and assuming that they are intelligent and present.

1. They are intelligent and have internal thoughts just like me.
2. They can hear me even if they don't look at me.
3. They can understand me even if they don't speak or behave how I expect.
4. They want to be included even if their body doesn't allow them to look interested.
5. They feel deeply and empathize even if they cannot communicate.

How can we presume competence?

- Talk *to* the person instead of *about* them.
- Talk to them normally in an age-appropriate way.
- Listen for their response, even if it's not what we expect.
- Honor what the person wants to talk about, rather than prompting them to say what we think they should say.
- Ask their permission before sharing information about them.
- Allow for extra processing time.
- Remember that *what a person says and what their body compels them to do to regulate their nervous system is not a measurement of their intelligence.*



Assuming INCOMPETENCE can result in the following:

- Talking down to the person, talking *about* them to people instead of directly to them, talking to someone like a baby or young child, known as “infantilizing”
- Missing or Ignoring communication, withholding access to age-appropriate material and education.



Advocacy

To support or argue for someone else



The ADA (Americans with Disabilities Act)

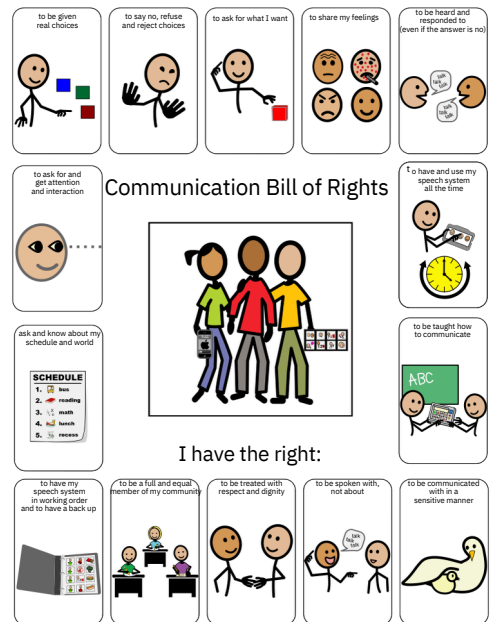
- The ADA provides public accommodations like those in transportation and employment to people with disabilities.

IDEA (Individuals with Disabilities Education Act)

Public Schools are REQUIRED to...

- Provide education to your child from ages 4-21 (other services through the Department of Health are available from birth to 3)
- In a general education classroom as much as possible (least restrictive environment)
- Create an Individualized Education Plan (IEP) if you qualify
- Parents have a right to participate and make decisions about their child's education

Everyone has a right to communicate!



From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). for meeting the communication needs of persons with severe disabilities. Asha, 34(Suppl. 7), 2-3. adapted by K. Ah

See Washington Autism Alliance and the Arc for legal resources

asha.org/njc/communication-bill-of-rights

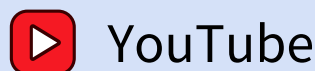
Disability Advocates



Bob Williams



Jordyn Zimmerman



Communication First

@CommunicationFirst • 1.92K subscribers • 50 videos

The official YouTube channel of CommunicationFIRST, the only nonprofit disability-led

communicationfirst.org and 3 more links

Subscribe

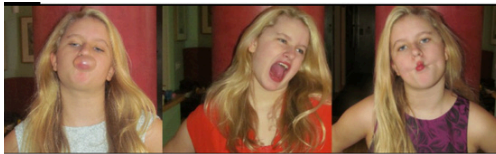
An Advocacy Organization for nonspeakers led by people with disabilities

Blogs and Movies from Nonspeaking Autistics

Interviews and Stories of people who use non-speaking means to communicate their thoughts.

Emma's Hope Book - A Blog

<https://emmashopebook.com>



Methods of Communication - My Research Paper

Posted on December 9, 2017 by emmausherhorne | 19 comments

"To what extent is it possible to compare the ways in which methods of communication are being taught to autistic students who cannot use spoken language to communicate their complex ideas?"

SUBSCRIBE

It's easy! Type in your email address and Emma's Hope Book will be delivered to your virtual doorstep.

Email Address

Visit Resources > Blogs and Blog Posts written by non-speaking Autistics (30) and other Autistic bloggers (50) to find a variety of blogs like **this** one.



Emma's Short Film - Unspoken

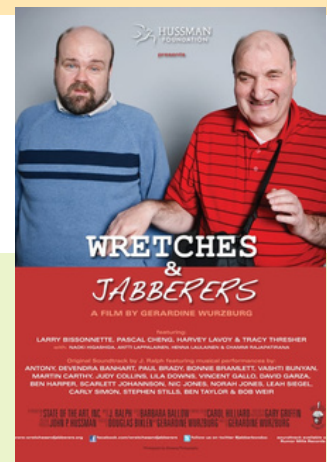
This is Not About Me - Movie by Jordyn Zimmerman

Her journey from an unrecognized nonspeaking Autistic person in a broken special education system to becoming a teacher herself (USA).



LISTEN

A FREE short film on YouTube by Communication First



Wretches & Jabberers (2015)

A documentary following two Autistic advocates as they interview Autistic individuals around the globe.

Interviews, Blogs and Stories from People with Autism

The-Art-of-Autism.com/ActuallyAutistic-Bloggers-List/

A large online collection of over 150 personal blogs written by Autistic individuals.

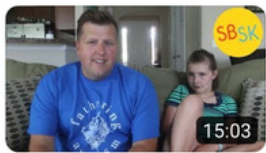
UnderCoverAutism.org

A highly informative blog written by an Autistic adult about what a sensory processing difference is and how it can feel (United Kingdom).



Toren Wolf

Autistic/ADHD teen who explains his experience and how parents can help their kids who may not be able to communicate their thoughts.



YouTube - SBSK

Playlist> Meet an Autistic Person
A YouTube channel that interviews people with a wide range of disabilities across a variety of cultures (USA). Kids, teens and adults.

Autism Level Up!

A website written by and for neurodivergent people to help explain symptoms related to energy regulation, emotional regulation, and sensory processing.



The Reason I Jump - Book, Film based on the book



A book written by Naogi Higashida, a 13 year old with Autism, nonspeaking and growing up in Japan.



A movie that follows three families of people with Autism around the world (England, India, Sierra Leone), with narration from the book.

Services you May be Recommended

Occupational Therapy

An occupational therapist (OT) can help your child with...



REGULATION (SENSORY INTEGRATION)

- Stimming, sensory seeking, avoiding sensation, tantrums, autistic meltdown, ARFID, food pickiness, emotional regulation, making schedules to use at school and home, etc.

MOTOR SKILLS FOR DAILY LIVING

- Dressing, utensils, toileting, coordination, “floppiness”, posture, big movement with the upper body and core, handwriting, cutting with scissors, etc.

SOCIAL SKILLS

- Understanding and interacting with others



Speech Therapy

A Speech Therapist (SLP) can help your child with....



COMMUNICATION, LANGUAGE

- Understanding language, self-expression via speech, a speech-generating device (AAC), sign language, picture boards, etc.

ECHOED LANGUAGE

- Echolalia via Gestalt Language Processing - Natural Language Acquisition

SOCIAL SKILLS

- Understanding and interacting with others.

ARTICULATION

- Help with making specific speech sounds if appropriate.



Physical Therapy

It's common for kids with Autism to have low muscle tone or to appear “floppy”. A Physical therapist (PT) can help your child develop muscle tone and coordination for skills like walking, running, and sitting.

⚠ Applied Behavior Analysis (ABA) Use caution!



A Board Certified Behavior Analyst (BCBA) can help your child manage behavior and develop positive strategies and life skills. Although this service is most advertised by insurance companies, it is highly controversial in its effectiveness and efficacy. Make sure to research the BCBA and type of ABA done. ABA is not certified by the American Speech and Hearing Association (ASHA) to treat Speech and Language disorders by or the American Occupational Therapy Association (AOTA) to treat Sensory Processing disorders. **Consult an SLP for communication strategies. Consult an OT for treatment related to sensory processing and life skills (known as ADLs).**

Other Therapies

It is common for children with Autism to have other concerns related to the digestive system, sleep and other neurological conditions. Consult with your pediatrician to find out what other specialist you may be interested in seeing.



Types of therapy intervention

Child-led therapy

Play-based therapy based on the child's interests, (Hanen program, Down to Floor, NLA intervention)

FOCUS

- Independent communication
- Self-advocacy
- Self-regulation skills
- Social interaction
- Following directions/sequencing steps
- Redirect harmful behavior to positive sensory strategies.

Often used in...

Speech Therapy

Occupational Therapy

Some newer BCBA's use child-led therapy



Compliance-based therapy

Structured or unstructured play, often with a daily schedule. Punishment or reward based on compliance (following directions from an adult)

FOCUS

- Reduce/redirect harmful behavior
- Reducing unwanted behavior, reinforce desired behavior
- Following directions
- Learning positive life skills

Often used in...

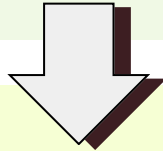
ABA/schools

Speech Therapy

Occupational Therapy



www.asha.org/njc/applied-behavior-analysis-and-communication-services



What you will see in Child-led therapy

- The adult begins by observing the child. The adult does not ask the child to follow an adult agenda, but follows the child as they play.
- The adult models skills based on the child's interests and regulatory/emotional state. The adult may "playfully interrupt" the play scheme to help with flexibility or build upon a skill. If this is distressing, however, the clinician will NOT continue to interrupt until the child has calmed.

Why NON-compliance (Child-led) works!

Child-led therapy works WITH the Autistic brain by using the child's interests to expand skills and help them gain confidence and flexibility at the child's pace.

What you can do while observing Child-led therapy

- Don't command or correct your child in session. The clinician wants to observe what your child will do on their own.
- Observe how your child responds to the clinician.
- Look for little "aha" moments of connection.





Fear vs Fact



My child is too old to start early intervention. It's too late.

Anyone can progress at their own pace with support at any age.

Will my child ever be able to talk?
Will they ever talk normally?

Some people develop speech and some are nonspeaking. Speech therapy and sensory support can help them communicate safely and effectively in their own way.

Will my child ever become independent and reach life milestones like getting a job and getting married?

Independence will depend on a host of factors. For right now, your child will develop at their own pace to become happy and healthy.

Will my child eventually act "not autistic?"

Attempting to act "not autistic," known as masking, is distressing for people with ASD. Check out interviews of Adults talking about the effects of masking on the Interview page.

My child doesn't respond. Does my child understand anything I'm saying?

Though a person's body may not obey their brain, they hear everything said about them and take it to heart.

Will my child be treated differently with an Autism diagnosis?

Diagnosis will open doors for more services and support. Advocacy and awareness can help you gain acceptance and support in your area.

Will my child make friends?

Will my family accept my child?

People with Autism often face challenges with social interaction and understanding other people. It is important to get involved with ASD communities and consider an ASD social group with speech or occupational therapy. Model and review social skills, but don't force your child to make eye contact or touch others.

A Word from our Parents here at Speech for Success

We asked our parents to write what they wished someone had told them when they were getting an ASD diagnosis for their child. Here's what they said.

“It’s going to be ok. You’re going to see your strength, how wonderful your child is, and how Autism shouldn’t be a fear.” -Shae

“Take everything one step at a time. Get connected with resources that are right for your child. Find what your child loves and embrace that.” - Alicia Littlemore

“There is nothing typical, and learning happens at their pace.”
- Anonymous

“As a parent this can feel really lonely and isolating at times. A strong network of friends and family can help.” - Anonymous

“Solid routines and habits make things loads easier “
- Anonymous

“A diagnosis is actually really helpful in starting to get the best services to help your child. Become comfortable speaking up and advocating for your child’s needs and rights.” -Anonymous

[Autismwellbeing.org.uk/resources](https://autismwellbeing.org.uk/resources)

Self-Care

A Guide for Caregivers

Advice from our Parents here at Speech for Success

We asked our parents to write what advice they wished someone had given them when they were getting an ASD diagnosis for their child. Here's what they said.

“Have courage.

It will not be an easy path. But acknowledgement/acceptance of the situation will help. Find resources. Your child will continue to love you unconditionally.” - Anonymous

“You’re not alone.

People are out there who will help you and guide. It’s ok to be scared and sad.” - Shae

“Find time for yourself

...and things that make you happy. Your child deserves the best version of you and that includes your physical and mental health. It’s not selfish.” - Anonymous

“Don’t hold back.

Share all the strengths and stressors, even if it seems “normal”. You’re not alone and you can get through it. Either way, the results will help you learn more about your amazing child.” - Anonymous

“Listen to your instincts.

You know your child best, and if any of the supports don’t feel like a good fit, it’s ok to find something different. Also, we have found that adding as many supports as possible has been great! Speech/OT/ Therapy.” -Anonymous

“Be present.

Appreciate all milestones no matter how small.” -Anonymous

First Steps Programs in WA State

*Note: UW and Seattle Children's currently have long waitlists for evaluations. Check resource lists like the Washington Autism Alliance to find other evaluating psychiatrists near you

UW Autism Center

Offers evaluations, education, and a variety of therapies.



UW AUTISM CENTER
INSTITUTE ON HUMAN DEVELOPMENT & DISABILITY
UNIVERSITY of WASHINGTON

ECEAP or HeadStart

FREE Developmental Preschools
Age 3-4



Washington State Department of
CHILDREN, YOUTH & FAMILIES

Respite Care



In-home daycare for your child. Many parents of children with ASD need breaks and services designed for kids with special needs. It's ok to take a break. Taking a break will allow you to strengthen relationships and recharge.

[AutismWellBeing.org.uk/resources](https://www.AutismWellBeing.org.uk/resources)

Free printable resources for topics like self-care in caregiving. Testimonials from caregiving parents for a child with Autism. Positive caregiving material.

Parent Recommended Resources Western WA, United States



learningtoplayllc.com

Small, parent-led play groups by age



WA Autism Facebook groups

Get connected to other parents and families



Arc of Snohomish County

***Most recommended by parents!**

A wealth of life planning resources



Washington Autism Alliance

A directory of resources available in WA state

Activities

- Sensory experiences at MOPOP
- Seattle Science Center
- Activities through The Arc



Parent Requested Resources - NOV 2024

Near Mukilteo, Everett, or Marysville

The following are frequently requested resources that do not yet exist in our area. If you are willing, please consider starting your own group for these activities.

- Moms and toddlers park play group for kids with ASD
- Spanish Speaking parents of kids with Autism group
- Spanish-speaking Autism social group for teens
- Autism Social group for teens-young adults
- Learn to Swim group for Autism - all ages
[Adaptive Swim - YMCA of Snohomish County 425-374-5779](#)
- Elementary Autism play group meetup
- Sensory/ASD friendly events and activities group

- Speech for Success is NOT PERMITTED to give out personal contact information to connect parents. If you are willing to start a group, you can share the group name in the lobby for others to join.
- If a group has been created, please let us know!