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PRESUME COMPETENCE

A PROFESSIONAL AND COMMUNITY HANDBOOK INFORMED BY *THE REASON I JUMP*

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INTRODUCTORY LETTERS

ADVOCACY WOOKBOOK ADVISORS

THE REASON I JUMP impact team have convened a wide-reaching community of autistic individuals from around the world to advise on the film and the educational materials. The guide opens with advice to professionals and community members in their own words. The team of advisors, all of whom are nonspeaking with the exception of Leo Capella, have also contributed words of experience and advice to a *Self-Advocacy Workbook* available at TheReasonIJumpFilm.com.

DEAR PROFESSIONAL,

Everyone thinks you are stupid if you cannot talk. You cannot access the curriculum and it was not possible for me to get a regular diploma. People see my body stims and either stare at me or laugh. Because the classrooms were not integrated, it was not possible to make friends with nondisabled peers. It is difficult to keep up with so many obstacles. Try to see my potential.

—EMMA BUDWAY, 23 YEARS OLD, USA, ADVISOR

DEAR PROFESSIONAL,

To fully support us in the way that we need it's extremely important to remember that we understand. You have so much to learn about our world and we would like the opportunity to teach you.

—BECKY DARROCH, 14 YEARS OLD, NEW ZEALAND, ADVISOR

DEAR PROFESSIONAL,

Our insides do not match the outsides. Listen to autistic voices instead. We are the evidence and the experts. Stop treating us according to books, but according to our advice.

—ADARSH GEORGE, 17 YEARS OLD, SOUTH AFRICA, ADVISOR

DEAR PROFESSIONAL,

We are so much more than meets the eye. Please think about where you get your information from. Only autistic people have the real information. Listen to us, hear our cry!

Yours in stimming,

—ZEKWANDE MATHENJWA, 14 YEARS OLD,
SOUTH AFRICA, ADVISOR

DEAR EDUCATOR,

It is important to presume competence. Everyone deserves access to an education, no matter what their disability might be. The measure of success should be access and not test scores. Many of us cannot demonstrate comprehension in traditional ways. It is incumbent upon you to present the information and be innovative and inclusive in the classroom. Separate is never equal.

—BEN MCGANN, 24 YEARS OLD,
USA, ADVISOR

DEAR PROFESSIONAL,

I am writing to you with a simple request. Please give respect to people with disabilities. There can be no true inclusive spaces without letting us in and giving us authority. We are not spectators in life.

—ZEKWANDE MATHENJWA, 14 YEARS OLD,
SOUTH AFRICA, ADVISOR

WELL, I WOULD NOT ADDRESS MOST OF MY PAST TEACHERS SO POLITELY.

They were horrible to me, and I am obviously still processing the years of trauma they inflicted on me. From that, I would advise all educators: Be a positive force in your students' lives! Believe in us. Presume competence. And respect them as humans.

What all support people should know is that we are complete humans! We are deserving of dignity and respect. We are highly intelligent and sensitive and perceptive. And we truly value our connection with other people.

—DANNY WHITE, 35 YEARS OLD,
USA, ADVISOR

I USUALLY WRITE THIS TO MY PROFESSORS IN COLLEGE:

I have moderate autism that affects my verbal communication and motor skills. I communicate by spelling on a letter board with the support of my communication partner. It's important to me that people understand that non-speaking doesn't mean non-thinking. Most people have trouble seeing me beyond my autism but dare to see me as no different from your other students. I have dreams of achieving my education and my independence.

—LISA VALLADO, 24 YEARS OLD,
USA, ADVISOR

DEAR PROFESSIONAL,

That was a weak greeting, let me try again. Konnichiwa or KonbanWa fellow colleague and perfectly suspecting victim, hajimemashite (that's much better)! Speaking as an autistic service user turned fellow professional (a rookie job coach), you have a serious set of challenges on your hands, and as someone who's worked with and volunteered alongside nonspeaking autistic people (directly and indirectly) I should know. So, in the spirit of continuous improvement (kaizen) my purpose in this letter is to hold up a friendly yet sharp mirror in order to make you think about the way that autistic people are treated.

To begin, let's all face up to an inconvenient truth about our shared standing with people at whatever point on the spectrum. In the UK research conducted by the All Parliamentary Party Group on Autism to mark the 10th anniversary of the Autism Act revealed that 11% of autistic people surveyed felt that hospital doctors had a good understanding of autism. The same survey from the report revealed that 10% of autistic people thought that social workers had a good understanding of autism. In fact, of the different types of professionals surveyed, none of them were viewed favorably by the majority of autistic people or their families who took part in the survey.

There is a huge amount of work to be done in order to bridge the gap between autistic people and professionals, even though it has to be said you're not for the most part evil people. On the contrary, judging from the people that I've met, you're perfectly well-intentioned people. However one of the most critical history lessons around autism and in fact around disability more widely is that good intentions don't automatically mean great actions.

So how do you counter this? Well I don't have all the answers, in fact in all honesty I have much to learn myself! Fundamentally, it is about showing respect, patience and kindness at all times as well as if and where possible interrogation to find out what solution works best before determining a solution for that person. Work with us, enable us to be ourselves and think about how you can help include more autistic people in our shared ranks. After all, autistic people, like other disabled people, are humans with rights whether under constitutions or the UN Convention of Rights of Persons with Disabilities and we must do what we can to assist them in realizing them.

At the end of the day let's all do our best to treat the people that we serve and each other as equals where possible knowing that to quote one of my favorite songs if not anthems: "as we climb to reach our destiny a new age has begun."

Many Thanks or, in honor of Higashida-San, domo arigato.

—LEO CAPELLA



USING THIS

HANDBOOK

FOR PROFESSIONALS AND COMMUNITIES

IN THIS HANDBOOK, WE'LL REFER TO PEOPLE WHO ARE NONSPEAKING, MINIMALLY SPEAKING, OR UNRELIABLY SPEAKING AS “**NONSPEAKING**,” BUT IT IS IMPORTANT TO UNDERSTAND THAT INDIVIDUALS COMMUNICATE DIFFERENTLY, AND THROUGH DIFFERENT MEANS.

[GO TO THE GLOSSARY \(P 23\) TO LEARN MORE.](#)

This handbook is designed to raise awareness, deepen empathy, challenge misconceptions, and improve practices of professionals and communities who work with nonspeaking, minimally speaking, or unreliably speaking autistic people.

Educators, social workers, home care support aides, medical professionals, staff at care and school facilities, and others, will see, listen, and learn from the extraordinary and rich diversity (and neurodiversity) of nonspeaking autistic people. Additionally the guide highlights Assistive Technology (AT) and Augmentative or Alternative Communication (AAC) such as Spelling to Communicate (S2C), letter boards, keyboards, stencils, and electronic devices, which assist nonspeaking individuals to fully communicate their thoughts, feelings, desires, questions, and wisdom. These tools and practices are not speech therapy, but they may provide access to communication, and they operate from the presumption of competence for all nonspeakers.

Throughout the Handbook, professionals and community members will discover writings and storytelling from *THE REASON I JUMP* (the documentary film and book) to reflect, discuss, and use as a springboard to strengthen practices and rethink everyday interactions to ensure a more just and inclusive world for everyone.

There are multiple ways to interact with and apply the content including:

- > **WATCHING CURATED FILM CLIPS FROM *THE REASON I JUMP* TO FOCUS DISCUSSION**
- > **USING QUOTES FROM THE BOOK AND DOCUMENTARY TO READ, REFLECT UPON, AND DISCUSS**
- > **ENGAGING WITH COMPELLING QUESTIONS FOR INDIVIDUAL AND GROUP LEARNING**
- > **APPLYING EXERCISES TO STRENGTHEN PRACTICES AND DEEPEN UNDERSTANDING**

**“I USED TO BE AFRAID THAT AS LONG AS I
WAS AUTISTIC,**

I’D NEVER BE ABLE TO LIVE PROPERLY AS A HUMAN BEING...

**I WROTE THIS STORY IN THE HOPE
THAT IT WILL HELP YOU TO UNDERSTAND**

**HOW PAINFUL IT IS WHEN YOU CAN’T EXPRESS YOURSELF
TO THE PEOPLE YOU LOVE.**

**AND WHEN THE LIGHT OF HOPE SHINES ON ALL THIS WORLD,
THEN OUR FUTURE WILL BE CONNECTED WITH YOUR FUTURE.
THAT’S WHAT I WANT ABOVE ALL.”**

— NAOKI HIGASHIDA,
THE REASON I JUMP (BOOK)

MAKING CONNECTIONS

AND BUILDING

EMPATHY

EDUCATOR RITA PIERSON ASKS,

“WOULDN'T IT BE WONDERFUL TO FIRST SEEK TO UNDERSTAND AS OPPOSED TO BEING UNDERSTOOD?”

In *THE REASON I JUMP* the full magnitude of this question is revealed. **Building trust within families and amongst friends, learning new skills, and fine-tuning our mindfulness practices with nonspeaking autistic students is the first step to building meaningful and effective learning relationships.**

INCLUSION AND BELONGING

Emma: “Ben puts up with a lot from me. He was my first friend. Our friendship requires some peace from the world.”

Berta McGann: “[Y]ou fast forward fifteen years and you realise that they have been friends for so long. That’s what makes this unique. How do you establish and sustain and nurture a friendship for twenty years with no spoken language?”



WATCH CLIP 1: INCLUSION AND BELONGING (RUNTIME 5:51)



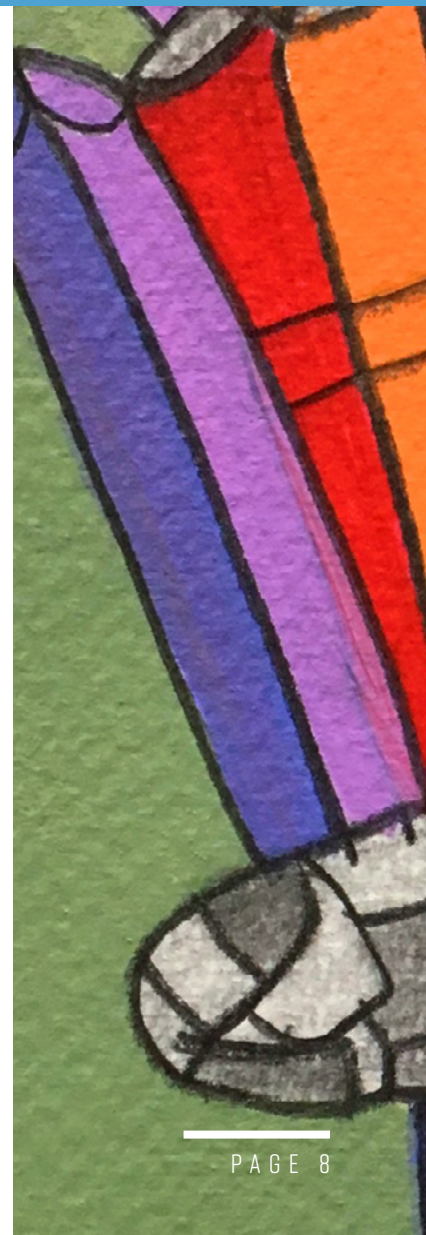
What moment(s) in this film clip deepened your understanding of the importance of inclusion and the feeling of belonging for nonspeaking autistic individuals?



READ, REFLECT AND DISCUSS QUOTES AND QUESTIONS

“Every time us autistic people do something that other people wouldn’t, it must make you wonder why....Please don’t judge us from the outside only. ... Spare a little time to listen to what I have to say. And have a nice trip through our world.”

— Naoki Higashida, *The Reason I Jump* (book)



“Now with the Tribe I have everything.”
— Emma Budway, *The Reason I Jump*

“The meaning of our friendship can’t be defined by words. Emma is my North Star.”
— Ben McGann, *The Reason I Jump*

“Right now Joss is having a joy that I will never come close to. Being with Joss is to live more in the moment.”
— Jeremy Dear, (Joss’ Dad), *The Reason I Jump*



ENGAGE WITH QUESTIONS FOR GROUP LEARNING

- > After watching the moving film clip from THE REASON I JUMP and reading quotes from nonspeaking autistic adults, what new insights do you have about companionship, love, friendship, and belonging?
- > How can you bring these ideas into your professional practice and everyday encounters with individuals?



STRENGTHEN PRACTICES AND DEEPEN UNDERSTANDING

1. Exploring empathy and belonging

- > **Watch:** Ted Talks Education: Rita Pierson [“Every kid needs a champion”](#)¹
- > **Read:** How does this talk resonate with you?
- > **Reflect:** What action(s) can you take as a result of Rita Pierson’s advice?

2. Understanding Naoki’s experience

Read Naoki’s full responses to these two questions from THE REASON I JUMP. After reading, take some time to respond in writing, or discuss with a colleague, how these personal insights on friendship, belonging, and relationship have shifted your understanding.

Question 13: “Do you prefer to be on your own?”

“Ah, don’t worry about him, he’d rather be on his own.”

How many times have I heard this? The truth is, I’d love to be with other people. I can’t believe that anyone born as a human being really wants to be left on their own, not really. No, for people with autism, what we’re anxious about is that we’re causing trouble for the rest of you, or even getting on your nerves. This is why it’s hard for just to stay around other people. This is why we often end up being left on our own.

The truth is, we’d love to be with other people. But because things never, ever go right, we end up getting used to being alone, without even noticing this is happening. Whenever I overhear someone remark how much I prefer being on my own, it makes me feel desperately lonely. It’s as if they’re deliberately giving me the cold-shoulder treatment.²



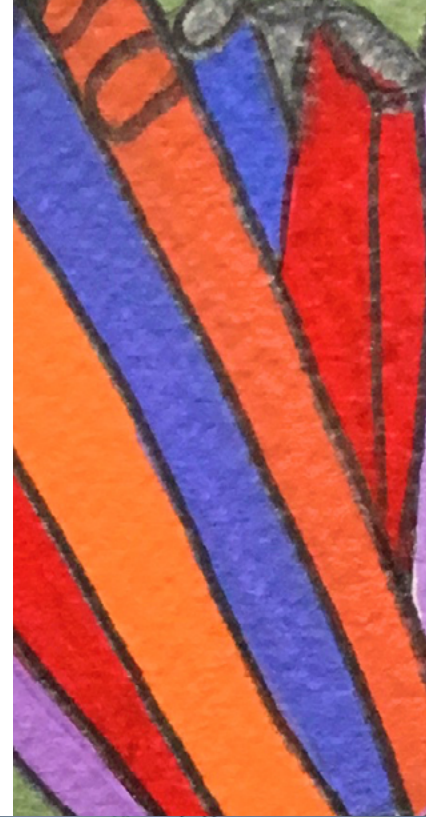
Question 14: “Why do you ignore us when we’re talking to you?”

If someone’s talking to me from somewhere far off, I don’t notice. You’re probably thinking, “Same here,” yes? A major headache for me, however, is that even when someone’s right here in front of me, I still don’t notice when they’re talking to me.

‘Not noticing,’ however is not the same as ‘deliberately ignoring.’ But often people assume I must be arrogant or ‘retarded.’ People around me always make me realize that I’m being spoken to by saying things like, ‘Say hello back, then Naoki,’ or ‘What do you say, then?’ So whenever that happens I just repeat what I’ve been told to say, like a mynah bird learning a new word. Even though I feel guilty toward the person who has spoken to me, I can’t even apologize, so I end up feeling miserable and ashamed that I can’t manage a proper human relationship.

A person who’s looking at a mountain far away doesn’t notice the prettiness of a dandelion in front of them. A person who’s looking at a dandelion in front of them doesn’t see the beauty of a mountain far away. To us, people’s voices are a bit like that. It’s very difficult for us to know someone’s there and that they’re talking to us, just by their voice.

So it would help us a great deal if you could just use our names first to get our attention, before you start talking to us.³



— AWARENESS OF THE CHALLENGES

Nonspeaking autistic youth are routinely misunderstood, underestimated, under-served, marginalized, and often adversely affected by this cycle even within the disability community. Their inability to speak reliably is perceived as a lack of intelligence or in the capacity to comprehend, communicate, and contribute to society. All of these assumptions are misguided.

Autistic nonspeakers are as intelligent as any of us, as aware of their environment, are listening, and can understand what is being communicated even though their behavior may sometimes not demonstrate it. This leads to isolation and segregation in schools. Through the words of nonspeaking autistic youth, THE REASON I JUMP corrects harmful misperceptions about autism and offers rare glimpses at the unique beauty of the autistic sensory experience.





WATCH CLIP 2: AWARENESS AND CHALLENGES - AMRIT (RUNTIME 2:51)



Discuss your understanding of and response to the challenges nonspeaking autistic individuals and families face. Did this film clip strengthen or challenge this understanding? How?



READ, REFLECT AND DISCUSS QUOTES AND QUESTIONS

Read and discuss these insights from nonspeakers and their families using the prompts suggested at the end of the exercise.

Communication

"I have a hidden disability. At first glance, one would not notice because my physical appearance is not different from any other woman my age. The challenge starts when people talk to me, and I am unable to make my body answer. I feel more frustration than I can express. In a split second, people assume that I am not intellectually competent, and their demeanor towards me changes completely. I become a victim, someone that needs help. One of my biggest struggles is when people start talking about me as if I were not present. Nothing hurts more than being ignored."

— Lisa Vallado, Advisor, *The Reason I Jump*

"I am able to speak but only a bit. Having some speech often lets me down because it does not reflect my true thoughts."

— Adarsh George, Advisor, *The Reason I Jump*

Question 8: "Why do you take ages to answer questions?"

(Excerpted from *The Reason I Jump* by Naoki Higashida)

You normal people, you talk at an incredible speed. Between thinking something in your head and saying it takes you just a split second. To us, that's like magic! So is there something wrong with the circuitry in our brains? Life's been tough for people with autism, pretty much forever, yet nobody's been able to identify the causes of autism. For sure, it takes us ages to respond to what the other person has just said. The reasons we need so much time isn't necessarily because we haven't understood, but because by the time it's our turn to speak, the reply we wanted to make has often upped and vanished from our heads. I don't know if this is making a whole lot of sense to you. Once our reply has disappeared, we can never get it back again. What did he say again? How was I going to answer her question? . . . Search me! And all the while, we're being bombarded by yet more questions. I end up thinking. This is just hopeless. It's as if I'm drowning in a flood of words.⁴

Meltdowns

Naoki Higashida wrote 'The Reason I Jump' when he was thirteen years old. And like my son, he was autistic and didn't speak. It's like cartography. He makes a map of his mind. There's an example where Naoki talks about the steps that he has to go through to understand that it is raining. And it would never occur to you if you're neurotypical, that you have to flip through this mental card index, connecting the sound, previous memories with the word 'rain' to work out what's happening now. You just know it's raining. The world that Naoki describes is different. Chaotic, swirling, raw and visceral. It's emotionally very taxing. Meltdowns can blow up out of nowhere. So that's where my son's living. And it's not easy.

— David Mitchell, *The Reason I Jump*



"I am often seen as unthinking and unfeeling. That is so far from the truth! I am highly intelligent and sensitive! Also, there is the misconception that I am deliberately acting out during my meltdowns. The reality is that I am frantically trying to calm down and I hate the situation even more than you do."

— Danny White, Advisor, *The Reason I Jump*

Question 19: "What are your flashback memories like?"

(Excerpted from The Reason I Jump by Naoki Higashida)

We do remember what we did, when, where, who we did it with and things like that, but these memories are all scattershot and never connected to the right order. The trouble with scattered memories is that sometimes they replay themselves in my head as if they had only just taken place—and when that happens, the emotions I felt originally all come rushing back to me, like a sudden storm. This is a flashback memory.

I know I have lots of pleasant memories, but my flashback memories are always bad ones, and from out of the blue I get incredibly distressed, burst into tears or just start panicking. Never mind that it's a memory from ages ago— the same helpless feeling I had then overflows and floods out and it just won't stop.

So when this happens, just let us have a good cry, and then we can get back onto our feet. Maybe the racket we make will get on your nerves a bit, but please try and understand what we're going through, and stay with us.⁵

Independence

"The future is an undiscovered country literally for us and our hope is that there will be a place for Joss, there will be a world, there will be a society, there will be an understanding for Joss that would mean that when we are not here, he will be okay. And that's...why we don't go to the future very often. Because the idea that Joss is going to be alone is really frightening."

— Jeremy Dear (Joss's Father), *The Reason I Jump*

"It is ok to be afraid. New things are scary; however, just because you once could not do something doesn't mean that you cannot do it later on in life.... Learn to find your own pace. Sometimes small steps can lead to a long journey. I advocate for myself in college by sending emails to all my professors before each semester starts letting them know that I will be in their classes. I make appointments with all my professors during the semester to demonstrate how I use the letter board and to let them ask questions and be familiar with how I communicate.

So far, I have not met a professor that was not respectful or unwilling to support me. They all are a little skeptical initially, but once they can see my fingers moving and spelling the answers, their doubts diminish.... In this new normal of COVID-19 and zoom meetings, making sure to leave the chat box available for me to type my responses and be attentive to read them and include them in the conversation."

— Lisa Vallado, Advisor, *The Reason I Jump*

Individually or in groups, discuss and brainstorm current professional practices and norms in the workplace when working with nonspeaking autistic students.

- How do these insights inform and change your understanding of the challenges nonspeaking autistic individuals and their families navigate on a daily basis?
- Given what you have read, watched, and discussed, what questions do you have about the changes you can make moving forward?





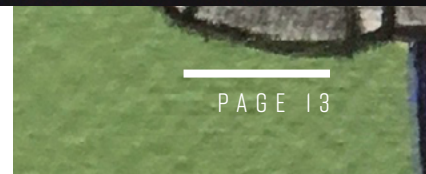
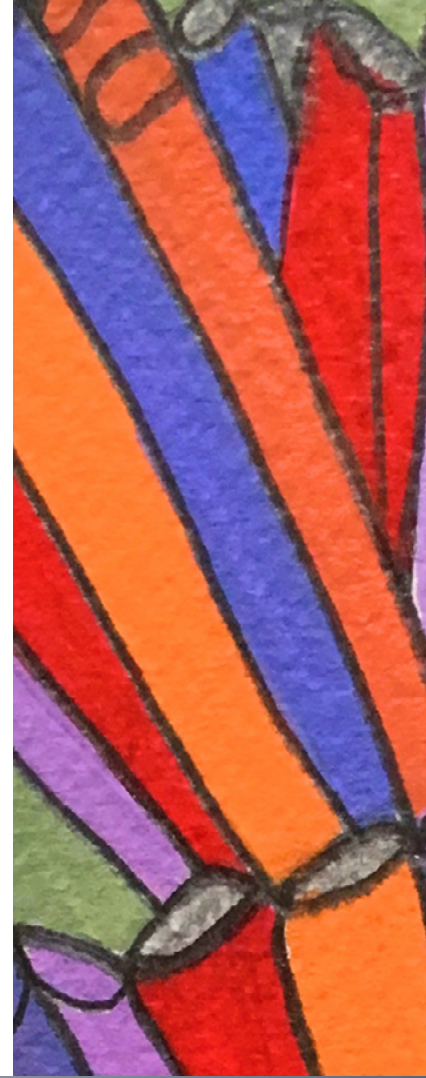
STRENGTHEN PRACTICES AND DEEPEN UNDERSTANDING

Review conditions that allow harmful norms and assumption to perpetuate and take time to reflect on your own practices working with or interacting with nonspeaking autistic people:

- Discounting competence of nonspeaking autistic people is promoted by some leading medical institutions. This misinformation perpetuates misguided practices and policies in schools and caregiving facilities
- Potentially harmful behavioral therapies begin in early childhood are embedded in education and caregiving programs and sometimes even promoted by leading autism advocacy organizations
- Prevalence of harmful stigma and misinformation about the causes of and cures for autism
- Profound segregation causes a general lack of public understanding and direct experience with autistic people and their families
- The physical behavior of autistic people is often misread. At times this can lead to misperceptions that they're unengaged leaving some parents unaware of the comprehension level of their nonspeaking autistic child

These harmful norms have large societal impacts:

- Isolation — Autistic youth are often segregated from their neurotypical peers at an early age and remain isolated throughout adulthood
- Autistic students are denied proper accommodations and education for their disabilities that meets their intellectual and creative levels. This a denial of their civil rights
- Autistic youth and adults are excluded from mainstream society and vulnerable to abuse and neglect
- Neurotypical youth and adults don't experience and benefit from the intelligence, creativity, and compassion of their autistic peers



A person wearing glasses is shown in profile, looking towards the right. The background is a bokeh of colorful lights in shades of blue, purple, and white. The text is overlaid on the left side of the image.

“I THINK WE CAN
**CHANGE THE CONVERSATION
AROUND AUTISM**
BY BEING A PART
OF THE CONVERSATION.”

— BEN MCGANN, *THE REASON I JUMP*



REFLECTING

ON MY OWN

PRACTICE

AMRIT LIVES WITH HER MOTHER IN NOIDA, INDIA. **FOR MANY YEARS, AMRIT'S MOTHER AARTI BELIEVED SHE COULDN'T COMMUNICATE WITH HER DAUGHTER.** AS AMRIT DEVELOPED HER ART, AND AFTER READING *THE REASON I JUMP*, AARTI CAME TO UNDERSTAND THAT ART IS AMRIT'S WAY OF COMMUNICATING WITH HER AND WITH THE REST OF THE WORLD.

This section provides quotes and questions, background information, film clips and exercises to delve into aspects of personal and professional habits and practices that can profoundly impact outcomes for nonspeaking individuals.

PRESUME COMPETENCE



READ, REFLECT AND DISCUSS: QUOTES AND QUESTIONS

I realised that it wasn't just art that she was doing, she was actually giving me the routine of her day and what all was happening. So she would draw what she was eating, she would draw other students around her, she would draw the landscape. And that is how the journey began.

— Aarti Khurana (Amrit's mother), *The Reason I Jump*

She used to have these obsessions. My feeling was that it is socially awkward. And I would try and stop her from doing that. But when I read Naoki's book, I realized what she must be going through. So it's difficult. I've acted so strange with my own child. I don't know how I fit into a mother's role. I've tried to stop her from being herself.

— Aarti Khurana (Amrit's mother), *The Reason I Jump*

She had so much anger in her, but there was no way she could tell us about it.

— Aarti Khurana (Amrit's mother), *The Reason I Jump*

People sometimes doubt spellers since they don't speak or don't have reliable speech and have difficulty controlling their bodies. They don't believe they are capable of the thoughts they are spelling. This is a flawed assumption based on the idea that speech is an indicator of intelligence.

— Elizabeth Vosseller⁶

- When you encounter a nonspeaking person, how do you assess their intelligence, or their competence?
- How does your treatment of that person reflect your assessment and assumption?



BACKGROUND INFORMATION

When professionals who support nonspeaking people assume that the people they serve are competent, they are making what psychologist Anne Donnellan termed the “least dangerous assumption.”

The criterion of the least dangerous assumption holds that in the absence of conclusive data educational decisions ought to be based on assumptions which, if incorrect, will have the least dangerous effect on the likelihood that students will be able to function independently as adults.⁷

The least dangerous assumption for nonspeaking autistic people is the presumption of competence. Presuming competence is the belief that nonspeaking people CAN and WANT to learn. It is then our job as professionals to teach them. When the professionals, community members, friends and family who offer care, connection, and education to autistic people assume competence, they are better able to provide support, care, and education that encourages their capacity and desire to learn, and their need to have a sense of belonging and purpose.



STRENGTHEN PRACTICE AND DEEPEN UNDERSTANDING

Elizabeth Vosseller, Executive Director of the International Association of Spelling as Communication, speaks of her own experience coming to understand that the nonspeaking autistic students she works with are able and willing to learn, and how that meant she, as an educator, had to change. **“It can be difficult, as a practitioner, to check your own assumptions. You have to be able to say, ‘for XX years, I was wrong,’ ...but which is worse, teaching them too much, or not bothering to teach them?”**

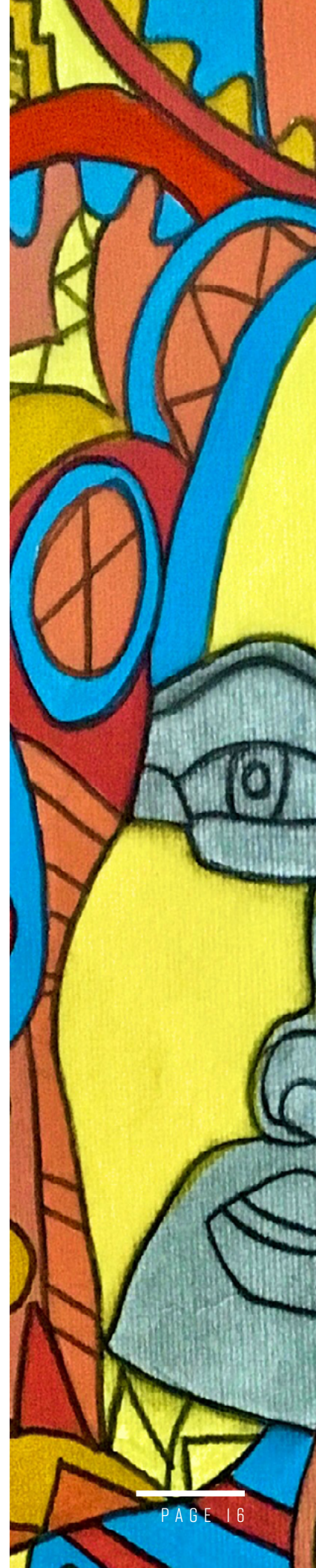


WATCH CLIP 3: PRESUME COMPETENCE



Watch this video [“Presume Competence”](#) from I-ASC, and complete one of the following exercise:

- Pick up a pen in your non-dominant hand (eg, if you are right-handed, use your left hand), and write your name.
- Take a pad of paper and look in the mirror, and try to write any sentence in the mirror.
- If you are in person, or online in a group, choose one person to be the writer, and have the group decide on two or three unusual words that person will have to use to write a sentence, like “giraffe” and “astronaut.” Then, have other members of the group make noise, for example by shouting nonsense words or singing random songs. In the midst of the ensuing noise, ask the writer to create an original sentence using the agreed-upon words.



After any of the exercises, reflect on or discuss these prompts:

- > Describe what the experience was like.
- > If someone who had never met you before only saw your writing from one of these exercises, what might they assume about you?
- > How do you understand the experience as it relates to that of nonspeaking people?

JOURNALING

Elizabeth Vosseller says, *“If nonspeakers are capable of spelling and are capable of intelligence, that really shakes the foundation of a lot of things that we’ve believed.”* Respond to that quote as a journal prompt. How might this insight change your practice?

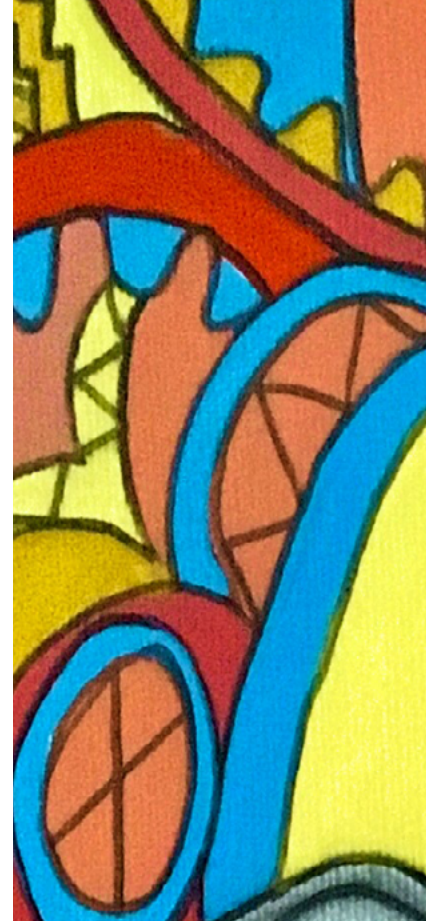
Practice Multiple Forms of Communication

“To live my life as a human being, nothing is more important than being able to express myself.”

—Naoki Higashida

Reflective Questions:

- > What are the ways in which you communicate your thoughts and ideas?
- > How do you communicate your strong emotions and feelings?
- > How much of your daily communication is functional communication (about meeting your basic needs), and how much of it is about expressing your thoughts and ideas?



— ALTERNATIVE AND AUGMENTATIVE COMMUNICATION AND SPELLING



READ, REFLECT AND DISCUSS: QUOTES AND QUESTIONS

“There are times when I can’t act, even though I really badly want to. It’s as if my whole body belongs to someone else. As if I’m remote controlling a faulty robot.”

—Naoki Higashida

“Many people who are autistic, their brain knows what to do but they can’t get it to their body. And it made so much sense, looking at it from more of a motor skills standpoint. Because speech is motor. Taking language out of the fine motor of the speech, putting it into the gross motor of the arm to point made a lot of sense.”

—Elizabeth Vosseller



“You talk at an incredible speed. Between thinking something in your head and saying it takes you just a split second. I have to speak in an unknown foreign language every minute of every day.”

—Naoki Higashida

- In your own words, describe why spelling or other communication techniques might be an option for nonspeaking autistic people.



BACKGROUND INFORMATION

Augmentative and Alternative Communication (AAC) describes multiple modes of communication for nonspeaking people, and broadly includes communication strategies including gestures, signs, vocalizations, using letter boards, symbols, or other aids, and communication aided by assistive technology (AT) like computers, handheld devices, or tablets. Selecting the right AAC(s) for any nonspeaking person relies on multiple factors, including that person’s needs, strengths, preferences, and learning and motor profiles, as well as access to training, technology, and trained professional support.⁸ **Presuming competence is a critically important part of choosing AAC to maximize a person’s potential, as is testing and trying multiple forms of communication.**

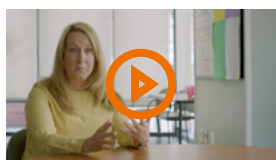
With regard to teaching and communicating using spelling, there are several different schools of thought. Some have evolved organically (as was the case with Naoki’s mother), and others have emerged through clinical practice. Though there has been some controversy about spelling and typing to communicate in different forms, for many individuals the results have been profound and life-changing.

“Spelling to Communicate (S2C) teaches individuals with motor challenges the purposeful motor skills necessary to point to letters to spell as an alternative means of communication. The goal is to achieve synchrony between the brain and body. Skilled and rigorously trained communication partners teach purposeful motor skills using a hierarchy of verbal and gestural prompts. As motor skills improve through consistent practice, students progress from pointing to letters on letter boards to spell to typing on a keyboard. Accordingly, communication moves from concrete to abstract as motor skills progress.”⁹

The film *THE REASON I JUMP* features spellers who have learned to communicate using S2C, assisted by professionals who have been trained through the [International Association for Spelling as Communication](#).



WATCH CLIP 4: ELIZABETH VOSSERLER EXPLAINS SPELLING TO COMMUNICATE (RUNTIME 2:30)



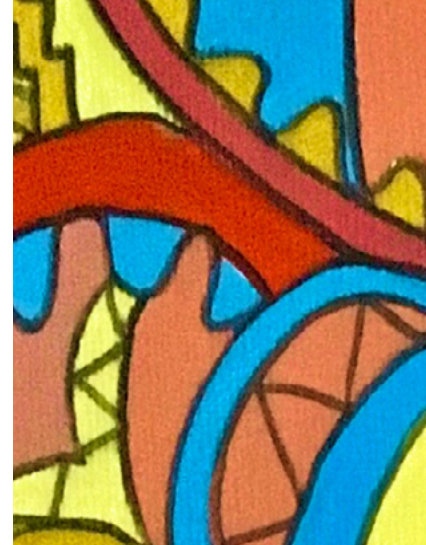
Elizabeth breaks down the mechanics of spelling to communicate; how it works, why it works (takes the process out of the fine movement of the mouth and places it in the gross motor of the arm), and how one goes about learning how to do it.





JOURNALING

- > Think back to a memory of your life, any memory, that has particularly affected you. It might be a wedding, a birth, a separation or meeting. How were words involved in the moment? How were words shared or communicated in the moment? What other kinds of communication existed?
- > What does this memory have to teach you about the role of communication in life? Relationships?



PROTECTING HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS

Donna: *Emma, what was education like before you had these classes to go to?*

Emma: *They wasted time.*

Donna: *Ok, Ben, how do you feel?*

Ben: *They have denied our civil rights.*

The United Nations [Convention on the Rights of Persons with Disabilities](#) (CRPD) was entered into force in 2008 with more signatories on its opening than any Convention in UN history. Article 21 of the CRPD, “Freedom of Expression and Opinion, and Access to Information,” states that parties to it “shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.”¹⁰

Though the United States has not signed onto the CRPD, [The Americans with Disabilities Act](#) requires schools, like many other public services, provide “effective communication” for their students with disabilities, which includes providing (AAC) for students with motor and developmental disabilities.¹¹

Legal protections like these offer autistic people and their families a basis on which to advocate for appropriate support in their home communities.¹²



SENSORY PERCEPTION: ART, NATURE, COLOR, MOVEMENT, AND SOUND

Autistic people experience the world, and communicate about their experiences, differently than neurotypical people.



READ, REFLECT AND DISCUSS: QUOTES AND QUESTIONS

“You may be looking at the exact same thing as me, but how I perceive it appears to be different.”

—Naoki Higashida

“I’m guessing that what touches you in nature is the beauty of trees and the flowers and things. But to us people with special needs, nature is as important as our own lives. However often we’re ignored and pushed away by other people, nature will always give us a good big hug, here inside our hearts. The reason is that when we look at nature, we receive a sort of permission to be alive in this world, and our entire bodies get recharged.”

—Naoki Higashida¹³

“There’s the moment (in the The Reason I Jump) where Amrit is looking at her pictures, which holds a lot of value. It is personally important to me, as I often don’t know what I’m thinking or feeling until looking back on a creative output, and also the re-living/re-telling that comes from revisiting things. The artistic process is a want for some, a need for some, and an unknown want/need for others.”

—Sumita Majumdar, Advisor to the *The Reason I Jump*

“When I’m jumping, it’s as if I’m shaking loose the ropes that are tying me down. as if my feelings are going upwards to the sky.”

—Naoki Higashida

- > What is new, surprising, or interesting to you about the sensory experiences described above?
- > Were there any that felt particularly resonant and familiar to you? In what way?



WATCH CLIP 5: SENSORY PERCEPTION



Choose a sensory experience, like sight, sound, taste, or movement. Challenge yourself to express your needs through your chosen sense.

Visit <https://the-art-of-autism.com/> to learn about and elevate artwork from autistic people.



FIGHT STIGMA, BUILD CAPACITY THROUGH COMMUNITY

JESTINA LIVES WITH HER PARENTS IN FREETOWN, SIERRA LEONE. ROLAND, HER FATHER, SAYS OF RAISING HER, **“SHE TAUGHT ME HOW TO BE A FATHER. THE KIND OF LOVE WE’VE GOT FROM HER JUST CHANGED YOUR WHOLE PERSPECTIVE OF LIFE.”** YET, DESPITE THE LOVE WITHIN THEIR FAMILY, THE STIGMA THE FAMILY COPE WITH BECAUSE OF THEIR COMMUNITY’S REACTION TO JESTINA’S NONSPEAKING, AND HER AUTISM BECAME OVERWHELMING.

Stigma against autistic people and nonspeaking people exists all around the world, is based on different cultural pressures, expectations, and ideals, and is extremely harmful and hurtful, resulting in isolation, segregation, and even violence. Stigma can be expressed through words and actions, and through systemic failures to provide the space and support to welcome and include autistic people in communities.



READ, REFLECT AND DISCUSS: QUOTES AND QUESTIONS

“Anywhere in the world, when you have a child with autism, there’s still a lot of stigma. As she grew up, I started to realize that Jes wasn’t looked at with love or empathy, it was with hatred and such negativity.”

—Mary Penn-Timothy (Jestina’s Mother), *The Reason I Jump*

“When I was small I didn’t even know that I was a kid with ‘special needs’. How did I find out? By other people telling me that I was different from everyone else. And that this was a problem.”

—Naoki Higashida, *The Reason I Jump* (book)

“We cannot just close our eyes to what we’ve seen. We need to do something about it.”

—Roland Penn-Timothy (Jestina’s Father), *The Reason I Jump*

“Nonspeaking students have heard enough of the bad, enough of everything - about themselves, about their outbursts. Educators will say those things in front of autistic students and assume they are not listening.

—Elizabeth Vosseller¹⁴

- Where, and in what ways, have you seen stigma against nonspeaking autistic people?
- Thinking back to a time when you were affected by stigma, how did that feel? What was your emotional and physical response to it?





WATCH CLIP 6: FIGHTING STIGMA



JOURNAL PROMPT

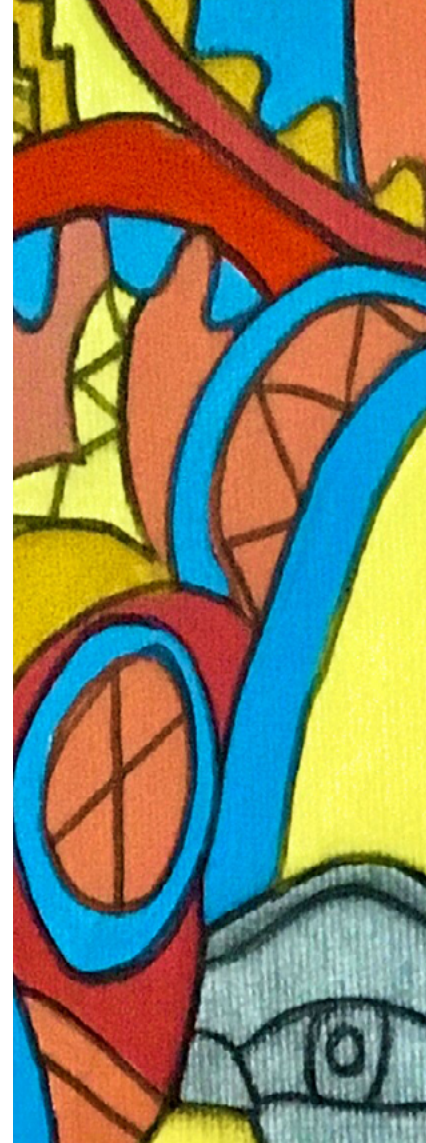
“We are at a major inflexion point in the trajectory of nonspeaking people. If we do not want to build another fortress (of bias), it means that parents and practitioners who are communication partners of nonspeaking people have to live up to a very high standard of personal practice, so as not to repeat the history of the past 8 decades.”

—Lakshmi Rao Sankar¹⁵

Read the blog post, [“Biases and How to Avoid Building the Next Stereotype”](#) on [i-asc.org](#). Using the blog as a starting point, respond to the following writing prompts:

- What are the ways that autistic people might encounter stigma and bias in your professional setting?
- Are there ways in which cultural stigmas or stereotypes about autistic people have influenced your thinking? What experiences or information helped you change those ideas? How did changing your ideas influence your actions?
- What kinds of learning experiences or training might support other neurotypical people who work in your setting to decrease stigma and bias?
- How might your physical space change to reflect those changes?

Jestina and her family fought the stigma in Sierra Leone by creating a community of families with nonspeaking autistic children, and eventually [opening their own school](#). Creating your own school is not available to every autistic person and family, but finding community is. [Read this example](#) of a classroom from the Growing Kids Therapy center connecting with a classroom at the nearby University of Virginia.



WATCHING

THE REASON I JUMP

It is highly encouraged to watch the documentary film *THE REASON I JUMP* directed by Jerry Rothwell and based upon the text of the same title written by then thirteen year old Naoki Higashida.

Visit www.TheReasonIJumpFilm.com to find out how you can view the film.

REFLECTING: QUESTIONS FOR BEFORE AND AFTER SCREENINGS

BEFORE WATCHING:

- > What do you expect this film to be about?
- > What forms of communication do you use to express yourself?
- > What does it mean to you to be able to speak?
- > What other methods of communication are available to you at moments when you cannot speak?

AFTER WATCHING:

- > What are your immediate thoughts and feelings about this documentary?
- > What did you learn that was new or surprising to you?
- > How would you describe what *THE REASON I JUMP* is about to a friend or family member?
- > Were there any insights or interactions in the film that changed how you think about autism, nonspeaking people, or other aspects of neurodiversity?
- > Filmmaker Jerry Rothwell used many cinematic techniques to bring to life the sensory experience that Naoki and others in the film described. What did you notice about those aspects of the film? How did they make you feel?
- > If you could share a message to Amrit, Joss, Ben, Emma, or Jestina, what would it be?
- > Aside from the spelling, what other methods of communicating did you see the young people in the film using?
- > What did this film teach you about, or remind you of as you consider your own way of perceiving the world? Was there anything that Naoki or one of the others described that felt familiar to you? Anything that felt completely unfamiliar?
- > How might the ideas raised in this film foster an educational system that is more inclusive of neurodiverse people? How might our broader society become more inclusive of neurodiversity?

INDIVIDUALS/ FAMILIES IN *REASON I JUMP*

- > DONNA BUDWAY
- > EMMA BUDWAY
- > JEREMY DEAR
- > JOSS DEAR
- > STEVIE LEE (DEAR)
- > AARTI KHURANA
- > AMRIT KHURANA
- > BENJAMIN MCGANN
- > BERTA MCGANN
- > DAVID MITCHELL
- > JESTINA PENN-TIMITY
- > MARY PENN-TIMITY
- > ROLAND PENN-TIMITY
- > ELIZABETH VOSSSELLER
- > JIM FUJIWARA



FIND YOUR

COMMUNITY

THE FILM TEAM CONSULTED WITH THE FOLLOWING ORGANIZATIONS DURING THE MAKING OF *THE REASON I JUMP*:

- > [ATHLETES WITHOUT LIMITS](#) (USA)
- > [AUTISTIC UK](#) - (UK)
- > [BRADSTOW SCHOOL](#) (UK)
- > [GROWING KIDS THERAPY CENTER](#) (USA)
- > [INTERNATIONAL ASSOCIATION OF SPELLING AS COMMUNICATION](#) (I-ASC)
- > [OPERATION HAND IN HAND](#) (GHANA)
- > [NATIONAL AUTISTIC SOCIETY](#) (UK)
- > [REYO PADDOCK SCHOOL](#) (GHANA)
- > [THE AUTISM EXPERIENCE GROUP](#) (UK)
- > [SIERRA LEONE AUTISTIC SOCIETY](#) (SIERRA LEONE)

The film's advisors have generated a [resource list](#) that features websites, organizations, and books, many of which are led and written by nonspeaking autistic people. While not a comprehensive list, it provides a good place to start for those who want to learn more.

AMPLIFY THE IDEAS OF NONSPEAKING PEOPLE:

Through the film, the book, the partner websites, or other organizations you find, support the nonspeaking community by sharing their stories and experiences with your personal and professional network.

TO BUY AMRIT KHURANA'S ARTWORK VISIT: WWW.MOJARTO.COM/ARTISTS/AMRIT-KHURANA-3529/

AUTISM

Autism is a neurological variation that occurs in between one percent and two percent of the population. The complex set of interrelated characteristics that distinguish autistic neurology from non-autistic neurology is not yet fully understood, but current evidence indicates that the central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the autistic individual's subjective experience more intense and chaotic than that of non-autistic individuals: on both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable.

Autism is a developmental phenomenon, meaning that it begins *in utero* and has a pervasive influence on development, on multiple levels, throughout the lifespan. Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing.

While the number of individuals diagnosed as autistic has increased continually over the past few decades, evidence suggests that this increase in diagnosis is the result of increased public and professional awareness, rather than an actual increase in the prevalence of autism.

Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree – sometimes quite obviously, and sometimes more subtly.¹⁶

Look at “[Understanding the Spectrum](#)” to see a visual representation of the spectrum.



IDENTITY-FIRST LANGUAGE

Identify-first language refers to identifying language where the condition, in this case “autism,” comes before other descriptors, like “autistic person” or “Deaf person.” [Many autistic people prefer identity-first language](#) in contrast to people-first language, which places the person before the condition or diagnosis, as in, “person with a disability.”¹⁷ As with any group that faces stigma or marginalization, the best way to get identity language ‘right’ is to ask and then honor a person’s individual preference with regard to how they identify themselves.

NONSPEAKING

Nonspeaking refers to individuals who do not have speech as a reliable or consistently reliable means to communicate their true thoughts. Use of speech is a motor skill, not a measure of an individual’s capacity for comprehension or communication.

“Nonspeaking autistic” is the language preference of the people whose stories are being told in *THE REASON I JUMP*. It is identify-first and is preferred over “non verbal,” since “verbal” in Latin translates to “without words.” Though they do not use speech to communicate, the people in the book and the film do have a lot to say.



MINIMALLY SPEAKING

An individual who is able to use speech to express some words, phrases or basic needs but may be able to communicate at a deeper level through pointing, spelling or other AAC.

NEURODIVERSITY

This term refers to the myriad ways in which brains function differently from what is considered 'typical,' without assigning judgment to those differences. Autism is one form of neurodiversity.



UNRELIABLY SPEAKING

An individual who is an unreliable speaker is not always able to use speech to communicate everything they want to say but wants others to know that they appreciate their effort to connect and recognize that they can't always know if there is more to share.

NEUROTYPICAL

Refers to brains that function within the ranges of what is statistically considered to be within the range of 'normal.'

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ENDNOTES

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WWW.THEREASONIJUMPFILM.COM

GUIDE DEVELOPED BY



Blueshift
Education

BFI PRESENTS AN IDEAS ROOM METAFILM VULCAN PRODUCTIONS AND RUNAWAY FRIDGE PRODUCTION A JERRY ROTHWELL FILM THE REASON I JUMP BASED ON THE BOOK BY NAOKI HIGASHIDA TRANSLATED BY DAVID MITCHELL AND K.A. YOSHIDA SOUND RECORDIST SARA DE OLIVEIRA
SOUND DESIGNER NICK RYAN DIRECTOR OF PHOTOGRAPHY RUBEN WOODIN DECHAMPS COMPOSER NAINITA DESAI EDITOR DAVID CHARAP CO-PRODUCER SAM PAYNE CO-EXECUTIVE PRODUCER SARA EDELSON EXECUTIVE PRODUCERS JOOY ALLEN PAUL G. ALLEN ROCKY COLLINS
JANNAT GARGI RUTH JOHNSTON CAROLE TOMKO LIZZIE FRANCKE STEWART LE MARÉCHAL JONNY PERSEY PETER WEBBER PRODUCERS JEREMY DEAR STEVIE LEE AL MORROW DIRECTED BY JERRY ROTHWELL

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