the reason i jump

SHARING MY STORY A SELF-ADVOCACY WORKBOOK BY AUTISTIC PEOPLE, FOR AUTISTIC PEOPLE

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"I LIKE TO BE SEEN.

BY THAT, I MEAN THAT I WANT PEOPLE TO TALK DIRECTLY TO ME AND WAIT FOR MY RESPONSE. I AM AWARE OF MY ENVIRONMENT EVEN THOUGH MY BEHAVIOR SOMETIMES MAY NOT DEMONSTRATE IT.

I AM LISTENING, AND I CAN UNDERSTAND EVERYTHING THAT IS BEING COMMUNICATED.

I LIKE TO PARTICIPATE IN THE CONVERSATION, AND I HAVE SOMETHING TO

CONTRIBUTE."

– LISA VALLADO, Workbook Advisor

OVERVIEW

The Self-Advocacy Workbook for THE REASON I JUMP is a resource for autistic people to support you in advocating for your own needs. It can be used as a stand-alone resource or as a companion piece to the feature documentary, THE REASON I JUMP, inspired by the book written by Naoki Higashida who is autistic and has difficulty speaking. The book itself is an act of advocacy. He writes: "PROBLEM IS, AUTISTIC CHILDREN DON'T HAVE THE MEANS TO EXPRESS THEMSELVES, AND OFTEN EVEN THEIR OWN PARENTS DON'T HAVE A CLUE WHAT THEY MIGHT BE THINKING. SO **MY BIG HOPE** IS THAT I CAN HELP A BIT BY EXPLAINING, IN MY OWN WAY, **WHAT'S GOING ON IN THE MINDS OF AUTISTIC PEOPLE."**

The workbook was developed in partnership with a group of autistic advisors, gathered by the film team, from around the world who come from diverse backgrounds, ages, perspectives and experiences. Some of the advisors can speak reliably and some use Assistive Technology or Alternative Communication (AAC) such as Spelling to Communicate (S2C). Each advisor was sent identical questions to answer. Their responses, thoughtful insights, varied experiences, and keen advice form the basis of this workbook and are excerpted verbatim. The list of questions is included at the end of this resource and can be used as a reference or to inspire further discussion and gathering of insights from your own community.

Advisor Leo Capella reminds us that autistic people are diverse, and that these personal reflections do not reflect autistic people as a whole. Rather, they act as an invitation to find community and networks that are meaningful to you, and help you on your journey towards self-advocacy.

You won't get along with every autistic person you meet no more than you would any other disabled person and that's absolutely fine. One autistic person I know once joked 'what do you call a group of autistic people together? An argument. To which I would add what do you call a group of autistic people and parents or personal assistants together: An argument waiting to happen!'

Having given you that warning I've also got to say that people on the autistic spectrum can be some of the most interesting, diverse and passionate people on the planet so do as you like but also don't do too much. So find the people and groups that connect (not necessarily match) your own style and try out different social groups to see where you fit in or not.

Above all find ways to go out of your comfort zone and remember that the biggest territory to explore will be yourself.

Throughout this workbook you will find:

> **REFLECTIONS AND ADVICE** FROM A WIDE VARIETY OF AUTISTIC ADVIORS

- > JOURNALING AND DISCUSSION PROMPTS TO EXPLORE YOUR OWN EXPERIENCES AND IDENTIFY SKILLS YOU WANT TO DEVELOP
- > **RESOURCES** TO HELP YOU CONNECT WITH THE GLOBAL AUTISTIC COMMUNITY, AND WHERE WE CAN ALL CONTINUE TO LEARN TOGETHER.

A Community Handbook for Professionals is available at <u>TheReasonIJumpFilm.com</u> and includes background information and skills-building for anyone who works with autistic people in community and professional settings.



ADVISOR INTRODUCTIONS



EMMA BUDWAY:

I am a 23-year-old autistic who spells to communicate. I am an unreliable speaker with a lot of stims. I have a wonderful apartment in Arlington, Virginia, that I share with an old family friend. Katie is in her last year at Stanford so I will need to get a new roommate in January. I have two older brothers and my parents live nearby and visit every day. Everyone is very loving and supportive. We do a lot together. I think it was difficult for everyone when I was young. I am proud of all of us for pulling through. Today, I feel we are quite close.

The way my brain works is different than most people. I experience the world in a chaotic way. I am not what I appear. I am smart, funny and a good friend. Try to ignore my stims*. I have so much more to say.

LEO CAPELLA:

I'm Leo Capella, I'm currently 34 and in my day job I currently work as a job coach for the National Autistic Society although I'm advising in a strictly personal capacity. In my evening role I try to write and finish stories, write poetry, and get my works published rather unsuccessfully, as well as do a bit of tasty campaigning on the side. I've been around the autism and disability scene winning awards both as a volunteer (student union representative) and as a professional (I was the employee of the year for the National Autistic Society in 2019) for over a decade (around fifteen years). I also hold a BA in Politics in the University of Essex and a MA in International Security from the University of Warwick. Other than that I was born in France and am currently transitioning (I hope) between places in the UK. On a historical note I also come from one of the first generations (age groups) of autistic people who were diagnosed when they were young, so that meant that we got a significant degree of "early intervention" and early training then had to figure out what that meant for our sense of self.





BECKY DARROCH:

My name is Becky. Chances are you have heard of New Zealand - that means I'm a Kiwi. Age is fourteen. My family includes myself and my Mum and Dad. Really hoping two guinea pigs will be joining us soon. Deciding what to say is perhaps easier if you had met me. It's one thing to reveal something about myself but having me only in words can only be a part of who I am. The best thing I would say about myself is my intelligence.

EMMA DALMAYNE:

I am Emma Dalmayne, an autistic mum to six wonderful children, five of whom are autistic. I home educate my youngest two. I run an organisation called Autistic Inclusive Meets here, <u>www.autisticinclusivemeets.org.</u> I also campaign against the abuse of autistic people. I report parents who use abusive pseudoscience quack cures on their children, and people who promote/provide them. I have written two books on autism and also blog.





ADARSH GEORGE:

My name is Adarsh George and I am autistic. I have a twin brother who is also autistic and a little sister as well. I am seventeen and live in Pretoria, South Africa. I am able to speak but only a bit. Having some speech often lets me down because it does not reflect my true thoughts.

*Stims are repetitive movements, behaviors, or sounds that can be self-soothing

ZEKWANDE MATHENJWA:

My name is Zekwande Mathenjwa and I am from Pretoria, which is the capital city of South Africa. I am fourteen years old and have two siblings, a brother and a sister. I am autistic and don't speak. I am really intelligent but only a few people know this because I am stuck in this body that makes me look slow.

BEN MCGANN:

I am 24 years old. I was born in NYC and spent my early years in Nairobi, Kenya. I started school in NYC before my family moved to VA. My dad travelled a lot so it was mostly me and my mom and sister and brother. And my therapists. I can swim a really long time. I learned to swim when I lived in Fiji. I would swim every day and learned to swim in an Olympic-sized pool. I prefer, though, to swim in a lagoon. I once found a bright red starfish when I was kayaking with my Mom in a lagoon.

WILLIAM TZIAVARAS:

My name is William T. I am twelve years old and I attend school on a full time basis. I am in the seventh grade. I was able to access the regular class with accommodations for my disabilities when I was fluently communicating on several devices including the low tech letter board. Before then I spent my days in segregated intensive support classrooms. During that time I was believed to be intellectually disabled. This is a commonly held belief by society of anyone with a communication disability. Add to that a motor planning impairment and sensory processing problems that autistics are famous for, and it would be impossible for most people to imagine us having any intelligent thoughts beneath the visible imperfections. I am fortunate to make a great enough impression on professionals in my life who vouched for me and helped me make my case for inclusion.

LISA VALLADO:

I am a 24-year old woman with autism attending Washington Adventist University, and my goal is to graduate in spring 2022 with a bachelor's in Biology. I am living with my parents while attending school. I enjoy running, playing hockey, surfing, traveling, and listening to music. I was born in Brazil and moved to the U.S. with my family when I was five years old. We lived in California for 14 years, and now we live in Maryland. I have two sisters. They are both married and unfortunately live far away from me. Last month, I became an American citizen, and I did the citizenship test using my letter board and a communication partner. I don't know if I was the first to use a letter board to take the test, but they were quite curious about the process.

I am an apraxic and minimally-speaking autistic man of 35 years of age. I am originally from Japan but grew up in California. My family is my life and inspiration. They are so loving and believe in me. I live with my mother and older sister, near my younger sister. Sadly, my father died in 2018. His spirit is with me always. I communicate by Spelling to Communicate (S2C) on a letterboard. I learned that I could use this about five years ago, but only have come to use it in my daily life this year. It has changed my life! I can now share my true thoughts and feelings.













A LETTER FROM LEO

Be aware that self advocacy will challenge and change you just as any form of conflict will do. I've seen a similar effect with non autistic parents including "the warrior moms" and I think, to paraphrase a Japanese text, we all use too much of the killing sword and perhaps not enough of the "life giving sword".

For my part, while I've become less opinionated and more curious in a lot of respects I've also become far more hard edged if not prejudiced about others, especially with certain "normal" autistic people to the point of being alienated by / afraid of them through my own experiences and battle hardened defensiveness. In fact part of my motivation for becoming a job coach is to try and address this defensive edge that pours into me like molten iron, even with once close autistic friends/ autistic people that I've admired.

After all, we can't use the old "Band of Brothers" quote from Henry V in the St Crispin's Day speech as a way of making and keeping friends all the time, even though this is what going into conflict can do to us.

So I would say to young campaigners look after yourself, reflect on what advocacy as a form of conflict does to you. Also don't forget that any form of self advocacy whether for yourself or beyond is not just about fighting whether on the offence or defence, it's about seeking the truth. After all, to counter my old Student Union president Hannah McFaull back at the University of Essex, liberation is more than just a battlefield, it's a twisty cragged coastal path through no man's land as much as it is a jungle with a positive promised land at the end of it.

-LEO CAPELLA, SELF-ADVOCACY WORKBOOK ADVISOR "I THINK WE CAN CHANGE THE CONVERSATION AROUND AUTISM BY BEING A PART OF THE CONVERSATION."

- BEN MCGANN, THE REASON I JUMP

PERSONAL

EXAMPLES OF

SELF-ADVOCACY

ADVISOR QUESTION:

WHAT ARE SOME EXAMPLES OF WAYS YOU HAVE ADVOCATED FOR YOURSELF AND YOUR NEEDS?

EMMA Budway:

I made the decision to move out into my own apartment and picked my own roommate. Both good decisions. I make decisions about my medications and health. I voted!! I decide how to spend my money and my free time. I decide what books I want to read and what classes I want to take.



BECKY DARROCH: I think saying what kind of reasonable adjustments at work is important and disclosing a person's disability is a good example of that. Another example is using hospital passports such as <u>this one</u> to communicate how medical staff such as doctors and nurses can work with autistic people while they're receiving medical care in hospital.

Tall order to try and advocate for yourself when you are not able to use your words. The letterboard speaks my true voice so I can reveal opinions that I need to express.

ADARSH GEORGE:

I have done lots of talking at my school to show them strategies that work for me. I recently wrote a song about how spelling changed my life.

ZEKWANDE Mathenjwa:

I help to advise my school the Sisu Hub about things that work best for autistic students in an educational setting, like changing the schedule to include more academics and getting an air conditioner. I also gave advice about engaging my body in class by giving me stuff to sort and organize.

I also wrote a letter to our president about autism:

Dear Mr. President and other members of the government,

My name is Zekwande Mathenjwa and I am non-speaking. Nobody believes that someone like me is capable of great things, but I am here to tell you that they are wrong. Help us to reach our potential by giving us access to services that presume competence and see how we are capable of changing the world. Thank you for listening to someone who knows autism from the inside out. LISA

WILLIAM

TZIAVARAS:

I advocated for myself when I insisted on a male roomate. Also, I do not want to be responsible for a child at this point in my life. I also am advocating to manage my own money.

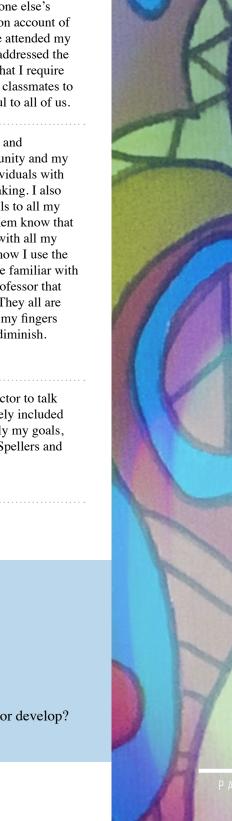
I belong to a group of great buddies called the No Nonsense Dudes. Last year we submitted ideas to a provincial advisory panel that advised the government on autism policy. It was the first time non-speakers gave input to the lousy program in effect. I feel that it neither helps nor harms to get yourself heard. It may not help me at this point but my insight and advice may have an incredible impact on someone else's life. One person's life having an improvement on account of my advocacy is all I could ever hope for. I have attended my IEP (Individual Education Plan) meetings and addressed the committee members. This has helped me get what I require to succeed at school. I also wrote a letter to my classmates to tell them how to connect with me. It was helpful to all of us.

One way that I advocate is by sharing my story and participating in leadership groups in my community and my University, so I can bring awareness about individuals with autism that are non-speaking or minimally speaking. I also 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.

DANNY WHITTY: One way I advocate for myself is telling my doctor to talk directly to me! It is important to me to be actively included in my health care decisions. I also tell my family my goals, worries, and preferences. And I am part of the Spellers and Allies Advocacy Network with I-ASC.



- > What does self-advocacy mean to you?
- > What are examples of times you have advocated for yourself?
- > What helped you in that moment and what was the result?
- > What are barriers and challenges to advocating for your needs?
- > Which advisor's experience is something you would like to try or develop?





ADVISOR QUESTION:

WHAT LESSONS HAVE YOU LEARNED, OR SKILLS HAVE YOU BUILT, THAT HELP YOU ADVOCATE FOR YOURSELF?

emma Budway:

Spelling to communicate is my best skill. I need to focus on independent typing. Need to write more and share our challenges and talents. The more I give presentations, the more confidence I have. We cannot give up – this is our life's work. Advocating has helped me to see our power.

From my own experiences and from being around the autism scene more widely I think that the key skills for autistic people to help advocate for ourselves more widely are:

- > ASSERTIVENESS: knowing when to assert yourself in different environments whether they're the office or at home. Some people, myself included, can be more skilled in asserting themselves effectively in one situation, maybe not so much in another.
- > PACING YOURSELF: know when to drive like "anything" and know when to give yourself a break. This skill can also help you stay productive and have the energy for speaking out. Mindfulness can also help.
- > **DECISION MAKING:** sometimes working through decisions using matrixes (tables with, for example, yes on one side and no on another side).
- KNOWING WHERE TO APOLOGISE AND WHERE NOT TO. Everyone makes mistakes and has things to learn. However there are times in life when you can not apologise for something whether it's who you are, a decision you make or a path that you choose.
- > THE LANGUAGE YOU USE: i.e. I will do instead of I will try to do.
- > BEING ABLE TO THINK CRITICALLY where possible and listening to other people.
- > BEING STRATEGIC and knowing when to pick fights as well as knowing when to avoid them. I'd highly recommend, if you can, learning a martial art or debating skills. If you can't then I'd say study them whether through watching TV, listening to the radio so you can figure out what strategies to use.
- > BEING ABLE TO ARGUE AND PROPOSE IDEAS CONSTRUCTIVELY: Saying, 'You're doing it wrong!' or 'That's not good enough' is not enough. You've got be able to say how you want something to change and provide an alternative. To point out what's wrong and what could be done is the art of advocating.

ABOVE ALL THE GREATEST SKILL OF SELF ADVOCACY IS TO KNOW AND ACCEPT YOURSELF WHICH ISN'T EASY. In fact it's the hardest thing that you'll ever do because it'll mean accepting there are things that you can't be as well as things that you can. However, if you can do that the rest will follow because you know yourself and the path that you take through life far better.

LEO Capella:

>

BECKY Darroch:

EMMA Dalmayne:

ADARSH George:

ZEKWANDE MATHENJWA

BEN MCGANN:

WILLIAM TZIAVARAS:



DANNY WHITTY The main lesson one should take from this life on the subject of advocacy is to learn to spell out your words.

I use my lack of social barriers and fear to campaign, I've worked undercover to expose quacks with the BBC and various other newspapers.

I have learned to spell to communicate which helps me to express my true self.

I have learned to spell which helps me to communicate my thoughts about autism and how our brains work.

I learned that guardianship does not mean that you speak for me and make decisions for me. I participated in a Supported Decision Making pilot program that helped me understand that I have rights to decide about my future. It is important to be informed of all scenarios before making a decision. You also have to be willing to listen to those you trust. It is totally OK to disagree but you have to be reasonable.

I learned to partner with a number of people on the letterboards which made my experience at school better in terms of being a credible communicator and advocate.

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. You may surprise yourself how your perspective may have changed. I used to feel embarrassed and uncomfortable reading in front of people; however, my professor encouraged me to try it in her communication class in college. Trying again in a different environment, and at another time in my life, made a difference in my perspective. It changed the focus from the sound of my voice to the courage and resilience that it takes for me to be vulnerable. I am very proud of who I am, and I have no reservation about giving speeches in front of an audience. It may not sound perfect, but it is my voice.

Self-advocacy is very dependent on confidence! It takes strong belief in yourself. And it takes integrity toward yourself. It helps to know that I am representing others like me! It adds to my determination and strength. I am steadily working on my skills to advocate for myself! It is so much more possible with a means of communication like spelling! It is also vital for me to have a staunch advocate ally. This means someone who will selflessly represent my expressed wishes and needs. For me, this is my CRP (Communication and Regulation Partner) and sister.

- > What skills for advocacy do you have that you are most proud of?
- > What skills do you most want to develop or grow?
- What resources can you access to work on building those skills? *Check the **Resources** section if you need ideas
- > Who can you ask to help you develop this skill and reach your goal?

"START BELIEVING. THE ROLE OF AN AUTISTIC PERSON CAN MAKE A DIFFERENCE IN THE WORLD."

- BECKY DARROCH, WORK ADVISOR

ADVICE

FOR YOUNG

AUTISTIC PEOPLE

ADVISOR QUESTION:

IF YOU WERE TO GIVE ANY ADVICE TO A YOUNG AUTISTIC PERSON, WHAT WOULD THAT ADVICE BE?

EMMA BUDWAY:

We need to stick together. Be brave.



The first thing I'd say is figure out WHO you are as a person and who you're not, how do you communicate with other people, what do you like, what don't you like. Then for better and for worse be yourself.

This also means developing and figuring out the following key senses:

> SENSE OF MISSION

In other words, what are you yourself aiming for? You could write up a mission statement with what are your goals in life and how you are going to achieve them.

> SENSE OF DESTINY

Being aware that there are things you cannot control and doing what you can do in the circumstances then seeing where everything plays out. There's a nice quote on a certain site called Samurai Archives by Uesugi Kenshin that describes exactly that kind of situation.

Also as my politics professor at the University of Essex (Professor David Sanders) used to say, think about two questions: What is your model (what's your way of thinking) and how would you know if you are wrong? It's fine to be wrong in life.

What can help is finding what you love. For me it's been politics and campaigning with all its opportunities and its problems, its current. For you it might be something else.

Having said that don't just aim to please everyone as you'll end up pleasing no-one including yourself. Because you won't be being yourself, you'll be mimicking other people instead, which won't work in the long run. So, ultimately be yourself. Do what you love with respect to other people around you and you'll ultimately do ok.



Start believing. The role of an autistic person can make a difference in our world.

EMMA Dalmayne:

ZEKWAND

WILLIAM

DANNY

BEN

MCGANN:

It's not you at fault, you are not disordered. The world is. You
shouldn't be ableist to yourself. Accommodating yourself
sensory-wise is not an admission of weakness. It is vital for
wellbeing.

Have faith that you will find a communication method that works for you. Never lose hope!

Don't be discouraged if some people don't see you for who you really are. The day will come when somebody sees your true potential so I can promise it will get easier. Real help is on the way. I will make sure of it.

You must find your voice. It is so important to be able to share information with others. I encourage you to learn to spell and read. I learned to spell and read with my tutors at home. If they won't teach you at school then learn however you can. Don't let anyone discourage you. It is important to look and listen.

They should learn about their own set of rights for communication. This will come in handy.

Never lose hope. Have goals for your life and work everyday day towards them. It is never easy, but it is possible as long as you never give up. Stay connected with other friends facing similar challenges and learn from each other. Having a community for support and acceptance is critical for your mental and emotional health.

I would tell them to be kind to their souls. And that they are not alone. I would encourage them to try Spelling To Communicate or some similar alternative communication approach. And I would tell them that they are worthy of their beautiful dreams!

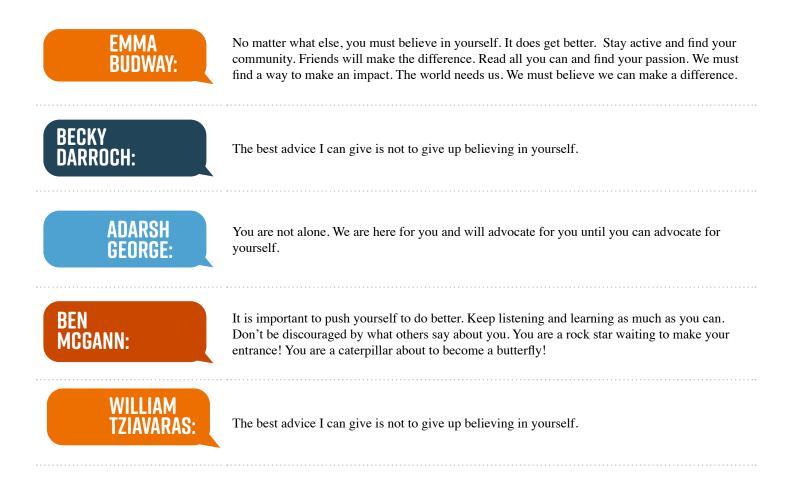
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- > Was there a particular piece of advice among these that stood out to you? Why?
- > What advice would you give to another autistic person?
- > What new ideas, goals, and dreams do you have after reading this advice from other autistic people?

ADVICE FOR YOUNG PEOPLE WHO ARE NON-SPEAKING,

MINIMALLY SPEAKING, OR UNRELIABLY SPEAKING

ADVISOR QUESTION: IF YOU WERE TO GIVE ANY ADVICE TO A YOUNG AUTISTIC PERSON WHO IS NON SPEAKING, MINIMALLY SPEAKING, OR UNRELIABLY SPEAKING, WHAT WOULD THAT ADVICE BE?



LISA Vallado:

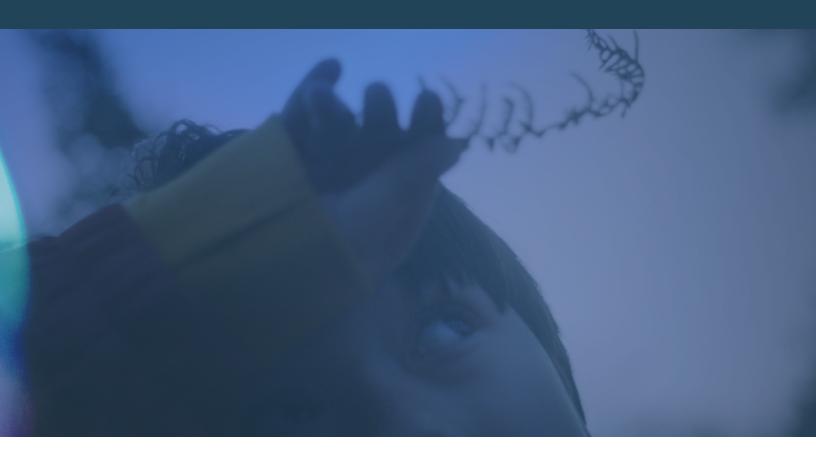
We share many of the same feelings and hopes of the speaking community such as acceptance, belonging, contributing, participating, having a voice and being heard.



That they have a friend in me!



- > What piece of advice is something you already tell yourself? What was new?
- > What does Ben's advice, "You are a caterpillar about to become a butterfly!" mean to you? Emma writes about finding your passion as a way to stay positive and happy. What are your passions? How did you discover this passion?
- > If you were to offer advice to any of the advisors in this workbook, what would you say?



"IT REALLY HELPS WHEN PEOPLE TALK **TO ME LIKE AN EQUAL."**

– EMMA BUDWAY, WORKBOOK ADVISOR

ADVICE FOR

FAMILIES, ADVOCATES, AND COMMUNICATION PARTNERS

QUESTION:

THINKING ABOUT THE PEOPLE AROUND YOU WHO GIVE YOU SUPPORT, WHAT WORDS OR ACTIONS FROM THEM DO YOU FIND MOST HELPFUL?

EMMA BUDWAY:

It really helps when people talk to me like an equal. Ignoring some of my stims is also helpful. Waiting for me to respond shows respect. Encouragement is not necessary. I know when you are taking me seriously.

Generally speaking I think the way to help autistic people is to try and make sure they're the ones in the driving seat in their own lives particularly as they're becoming adults. This can mean:

LEO Capella:

BECKY

DARROCH:

> AVOIDING THE WORDS "I THINK" if you can (as they can become loaded to the point where they're a control reflex) and instead ask "what do you think?" and be prepared to work through things and decisions with them. Sometimes you might be asked to be a sounding board for ideas.

> ALSO REMEMBER that the way you might see someone that you care about might not be the way that they see themselves. With their permission try to find out more about the way they see themselves.

> BEING CALM AND PATIENT, (remember Autism can be primal) providing reassurance where needs be particularly when autistic people are running through decisions that they've made. The shock of doing something that might set them (in my case switching from full time to part time) or crossing through a threshold can be a particularly nerve wracking experience for us.

Also as my politics professor at the University of Essex (Professor David Sanders) used to say, think about two questions: What is your model (what's your way of thinking) and how would you know if you are wrong? It's fine to be wrong in life.

The words that are the most helpful start with love. The story of an autistic individual is often filled with self recriminations. The actions of those around you can help you in their time and support to rise above yourself.

Just being there, it's good to have people that understand me and my sensory needs.

ADARSH GEORGE:

EMMA

DALMAYNE:

Real encouragement comes in the form of presuming competence, not speaking to us as if we don't understand. Always address us with respect and kindness.

ZEKWANDE MATHENJWA

I have learned to stick with those who see what I can really do. Nothing beats seeing how smart I am and really talking to me accordingly. Talking to my body also helps, my body needs direct instructions like 'lift your arm and open your fingers' instead of 'pick it up.' I struggle with motor planning, so the little steps help.

BEN MCGANN:

WILLIAM Iziavaras:





My mom believes I am competent. She always asks before disclosing information about me, even funny stories. I appreciate this so much because it shows that she respects me as a human being. I am fortunate to be surrounded by people who love and support me. I am happy that my mom insisted I learn how to follow instructions. ABA (Applied Behavior Analysis) Therapy was hard but it helped me understand others' expectations, even when I lacked the motor planning to comply. It is helpful for others to have high expectations.

They must be patient, calm, smart, and they must have my best interests at heart. I depend on them and so does my reputation.

My family is my support base, starting with my parents and sisters. I also have aunts, uncles, and cousins that support me at different levels-some with communication and some helping me navigate the world. I also have therapists and other professionals who help me increase my communication skills from pointing to typing and being more independent. I love my friends that also use the letter board to communicate. Their friendship fills my soul with peace and appreciation for life and friendship. I am very blessed by having a community that loves me and supports my goals and dreams. The action I appreciate the most is when people talk directly to me and wait for my response. I also value when the focus is on fostering an environment of respect and inclusion and making small changes tha allow all to participate. For example, 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.

My older sister and CRP is an amazing ally to me! She truly cares about my real voice and my rights. She empathizes deeply with me. Even if she disagrees with me or doesn't like what I say, she faithfully works to make my voice heard. It means the world to be able to trust her integrity and respect toward me!

In my family, it is so helpful when they can see my meltdowns as I do – internal struggle that is hard to control or even understand. It also helps to hear their praise and joy in my positive times. Their love surrounds me!

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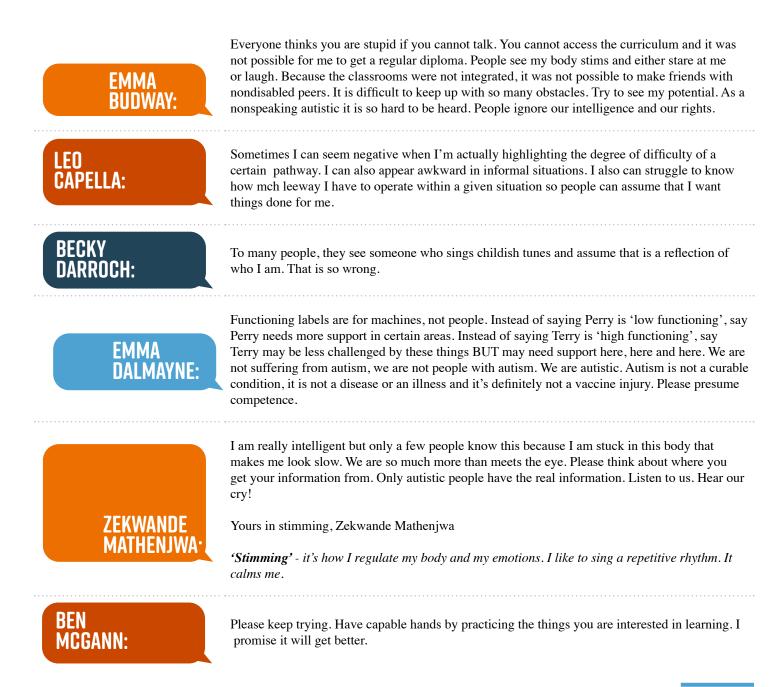
- > What words or actions from the people who support you help the most?
- > What are ways you can help your family and support people understand more about you?
- > What question have you always wanted to ask your family or support person?



MESSAGES FOR

NEUROTYPICAL PEOPLE

QUESTION: WHAT IS SOMETHING PEOPLE OFTEN MISUNDERSTAND ABOUT YOU?



WILLIAM TZIAVARAS:

They think I am not as autistic as other non-speakers that cannot communicate like I do. When in fact I didn't always know how to communicate either. My ability is learning the motor memory to point to the 26 letters needed to spell anything I want. Other nonspeakers can learn this with daily practice. I think the misunderstanding has something to do with a presumption that people with communication problems are cognitively impaired. And also that the more a person can't talk, the more it is falsely presumed that they are more cognitively delayed.

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.

We share many of the same feelings and hopes of the speaking community such as acceptance, belonging, contributing, participating, having a voice and being heard. I feel that people cover my body with all their assumptions and can no longer see the naked, authentic version of me. They can only see the image they created with all the layers they added. They see their version of me, not who I am.

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.





LISA

- > What messages do you want most to communicate to neurotypical people?
- > What are some ways you might go about communicating those messages?
- > After reading the messages of these advisors to neurotypical people, what would you include that is missing?



"I AM OFTEN SEEN AS UNTHINKING AND UNFEELING THAT IS FAR FROM THE TRUTH."

- DANNY WHITTY

NETWORKS, ORGANIZATIONS, AND RESOURCES TO LEARN MORE

This is a list of resources collected from the workbook advisors and during the making of the film. It is not meant to be a comprehensive list. Visit <u>TheReasonIJumpFilm.com</u> for more.

NETWORKS AND ORGANIZATIONS

- > <u>Autangel</u> Growing Autistic Community (UK)
- > Autistics for Autistics (A4A Ontario) (Canada)
- > <u>Autistic Inclusive Meets</u> Advisor Emma Dalmayne's UK-based networking organization
- > Autism Inclusivity Advisor Emma Dalmayne's Facebook group
- > Autistic Self Advocacy Network (ASAN) (USA, International)
- > Autistic Strategies Network (South Africa)
- > Communication FIRST (USA)
- <u>The Disability Archive</u>, Centre for Disability Studies, the University of Leeds (UK)
- > Fierce Autistics and Allies (USA)
- > Flow Observatorium, Support for neuro-divergent artists (UK)
- > Growing Kids Therapy Center (USA)
- > International Association of Spelling as Communication (I-ASC)
- > National Autistic Society (UK)
- > Sisu Hub Facebook Page (South Africa)
- > <u>TASH</u> Disability Advocacy (Based in USA, International)
- > Zekwande Foundation Advisor Zekwande Mathenjwa's new foundation to support his advocacy work in South Africa and beyond

BOOKS

- > I-ASC Book List for Nonspeakers
- > Assimakopoulos, *Lia*, *Life in Letters: A Book About Autism* (Lia Assimakopoulus, 2018).
- > Grinker, Roy Richard, Nobody's Normal: How Culture Created the Stigma of Mental Illness (W.W. Norton & Company, 2021)
- > Kedar, Ido, *Ido in Autismland* (Ido Kedar, 2012).
- > Peña, Edlyn, Ed., Leaders Around Me: Autobiographies of Autistics who Type, Point, & Spell to Communicate (Edlyn Vallejo Peña, 2019).
- > Prizant, Barry M., Uniquely Human: A Different Way of Seeing Autism (Simon & Schuster Paperbacks, NY, 2015). Silberman, Steve, Neurotribes: The Legacy of Autism and the Future of Neurodiversity (Avery, an imprint of Penguin Random House, NY, 2015).
- > Wady, Paul, Guerilla Aspies: A Neurotypical Society Infiltration Manual (Free Autistic Press through Dark Windows Press, 2014).

LEO CAPELLA:

The thing about any autism, or for that matter, disability charity/organization generally is that there is going to be a level of calculation involved about how closely you get involved with them if you decide to use them. Factors involved in making that calculation include

- What impact have they had at local or national level? (check search engines or local newspapers)
- > What impact could they have? (hard question I know)
- Do they provide services or information that are useful for you?
- Are they stable enough that you're going to feel comfortable with them?
- How much clout or power do they have with people who make decisions?
- Do they use any approaches or methods that you disagree or agree with?
- > What values do they have as an organisation and are they in line with your own ones?
- > What's going on behind the scenes?

I could go on but the main thing to think about is whether the costs or bad things outweigh those benefits of getting involved with that organisation i.e. using services from it or volunteering for it etc. Also bear in mind your opinion of an organisation can change over time depending on how the organization operates and what it does.

ADVISOR QUESTIONS

Tell us a little bit about yourself: where are you from, your age, and a bit about your family.

What is something you'd like everyone to know about you?

What is something people often misunderstand about you?

If you were to give any advice to a young autistic person, what would that advice be? (or) If you were to give any advice to a young autistic person who is non speaking, minimally speaking, or unreliably speaking, what would that advice be?

This guide is about advocating for yourself and your needs. What are some examples of ways you have done that?

What lessons have you learned, or skills have you built, that help you advocate for yourself?

Thinking about the people around you who give you support, what words or actions from them do you find most helpful?

If you were to write a letter that started, "Dear Professional..." what would you tell the educators, social workers, doctors, and others who support you and other autistic people? What are the most important things for them to know? *The "Dear Professional" letters are included in the Practitioner's Guide

What else do you think is important for other autistic people to know?

Are there any books, websites, organizations, social networks, or other resources that you would recommend?



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