



May 2020

Introduction

The main goals of *Communication Support World Network* newsletters are to share what is happening in AAC around the world and to promote networking.

The content of this edition focuses on news of international and national communication projects, articles and links to resource material, with practical solutions provided by many people around the world, kindly sharing information in this time of global crises of COVID-19 pandemic and of climate change.

A global network in action!

by Co-editors Nadia Browning (Chair of ISAAC Council) and Dorothy Fraser (Chair of ISAAC BUILD Committee)

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THE COMMUNICATION BOARDS PROJECT: The Philippines

RESPONDING TO THE COMMUNICATION NEEDS OF PATIENTS WITH COVID-19 IN THE PHILIPPINES

by Barbara F. Munar, MRS-SP, CSP-PASP

This article is about how the Philippine Association of Speech Pathologists (PASP), through its Augmentative and Alternative Communication Special Interest Group (AAC SIG), has been responding to the communication needs of patients with COVID-19 in the Philippines. The author is the head of the PASP AAC SIG.

While I browsed through social media, a post by a healthcare worker – a nurse – caught my eye. She described how, at one moment during one of her shifts, her patient with COVID-19 raised his hand as if he was asking for a high five. She then asked if it was a high five he wanted, the patient raised his hand again, but this time longer. She mirrored the patient's raised hand and the patient reached out to her hand and held it. She then realized that the patient was signalling "wait," to not leave yet, and to pray for him.

I reached out to the nurse and sent her a message in order to get first-hand information on how they communicate with their patients with COVID-19. The masks and PPEs that healthcare workers put on and the enhanced respiratory supports for some patients with COVID-19 are expected to create communication barriers between patients and their healthcare workers. She responded that her hospital—a private institution—have communication boards and electronic tablets available for patients to use, provisions that some hospitals in the country may have as well. However, there are many more hospitals around the country that do not have access to such communication tools and supports that could address the communication barriers between patients and healthcare workers. Moreover, with the 661 speech-language pathologists¹ listed in the database of the PASP, 7.8% are AAC specialists², and approximately 9-10% of this figure work in hospitals³. Majority of these speech-language pathologists in the Philippines practice in the national capital region, leaving many hospitals in the areas outside Metro Manila without these communication specialists in their employ.

With increasing number of Filipinos afflicted with COVID-19, it was imperative that healthcare workers throughout the country be provided with resources to meet the communication needs of their patients. Effective and efficient communication between patients and their healthcare workers can lead to less stressful hospital stays and more efficient patient care.

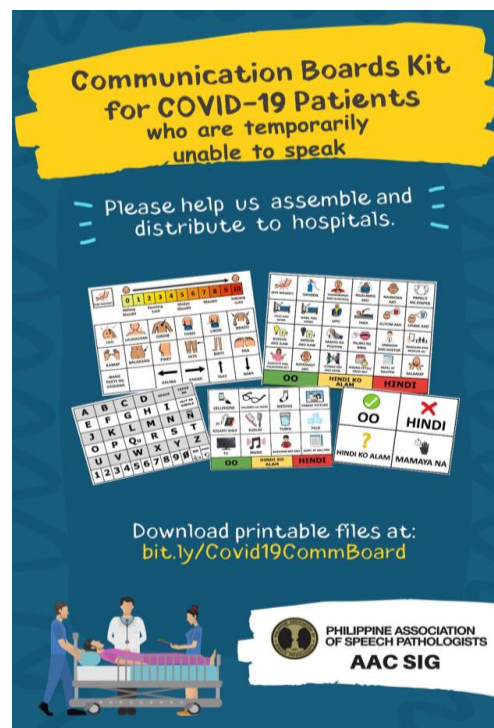
¹ www.pasp.org.ph (2020)

² PASP (2020)

³ PASP (2020)

The image of a COVID-19 patient trying to communicate his needs through gestures was the catalyst for the Communication Boards Project of the Augmentative and Alternative Communication Special Interest Group (AAC SIG) of the Philippine Association of Speech Pathologists. The aim of the project was to develop soft copies of communication boards that will be uploaded to an online storage service and will be made accessible to the public. Volunteers can download, print, and assemble the communication boards kit and distribute them to hospitals within their communities. The goal was, through the help of volunteers, hospitals throughout the country will receive copies of these communication boards.

Word was immediately sent to members of the AAC SIG to seek their assistance in developing the communication boards. Without hesitation, colleagues volunteered to do research and find references to jump-start the project. The AAC SIG is grateful to groups like Patient Provider Communication⁴ for making their online resources free. Their template and instructions allowed the group to develop the boards quickly. More colleagues reached out to help with the layout and editing of the boards. Others contacted healthcare workers who work directly with patients in critical care units. Thus, we were able to gather the vocabulary needed to develop the boards that were suited to our culture. In 24 hours, the initial set of Filipino and English communications boards, together with instructions on how to use and



The PASP's poster: Call for Volunteers

⁴ The resources of www.patientprovidercommunication.org were references for the communication boards that the PASP AAC SIG developed.

assemble the kit, were uploaded to an online storage service. The next step was to send out word to members of the association to spread the word about the project.



The communication boards kit printed by Project Shield PH, a privately-led movement by individuals leading multiple family volunteers providing face shields to frontline workers

As the Philippines is a multilingual country, it was also necessary that the boards be translated to other Philippine languages. Members of the association again volunteered to translate the communication boards.



Volunteers from Cebu City, Philippines, printing the communication boards for hospitals in Visayas

Since the whole country was placed in an enhanced community quarantine, looking for materials to print the boards became a problem. The suspension of public transportation posed as logistical issues in transporting the boards to hospitals. Thankfully, the information dissemination campaign done by the association was effective in reaching out to volunteers. Via professional networks, a non-government organization reached out to help PASP in printing and delivering the communication boards to hospitals in Metro Manila. SLP groups in the provinces of the Philippines also printed the boards and distributed them to hospitals in Southern Luzon and in the Visayas and Mindanao regions.

The project gained more momentum when a local media group published the story about the Communication Boards Project online. This produced a sudden surge of interest from private citizens and local printing companies. They reached out to the association and volunteered to print and assemble the communication boards. Others volunteered to bring the boards to hospitals in need; some offered to translate the boards to other Philippine languages; and a number of individuals also donated funds to help the association print the boards.

The project had continued to evolve. As many healthcare workers were thought to be unfamiliar with the use of message boards, the group created tutorial videos and uploaded



Volunteers from Davao City, Philippines, assembling the communication boards for hospitals in Mindanao

these to the online storage as well. The videos also included information on other basic strategies to support communication between patients and healthcare workers. Soon other local media groups wrote about the project, facilitating its spread through social media. In no

time, SLP colleagues from several parts of the world such as Singapore Vietnam, USA, Canada, Guadeloupe, the Cayman Islands, Austria, and Kosovo reached out to the association and requested to use, adapt, and translate the boards into their languages.

As of mid-April, at least 50 hospitals around the country have been given communication boards. However, this figure was only from volunteers that the association was able to connect with. The link to the online storage has been visited more than 5000 times from different places. Thus, it is safe to assume that more hospitals have been given the boards through the efforts of volunteers.

To date, even as the entire world stayed home in response to the ongoing pandemic, the boards have been translated to eight Philippine languages and four foreign languages. Work continues as these are still being translated to several more Philippine languages and foreign languages. The group also continues to collect feedback from healthcare workers in order to improve these boards and help develop new ones basing on patients' needs.

“Bayanihan” (pronounced *buy-uh-nee-hun*) is a Filipino word derived from the word *bayan* which means town, nation, or community in general. It signifies the spirit of communal unity and mutual assistance: helping each other to achieve a common goal; doing something *for* the community *with* other members of the community. It was *bayanihan* that made it possible



The communication boards being delivered to different hospitals in the country

for the project to work. Without the willingness of other people to lend a hand, to offer their resources, or to share their talents, the objectives of the project would not have been met.

The project had also opened up opportunities to touch base with colleagues from our neighbour countries and other parts of the world. It is with hope that this will bring more collaborations that will strengthen support networks for individuals with complex communication needs across nations.

What this experience had also taught us was—the work is not yet done for our countrymen with complex communication needs. The vision of the PASP AAC SIG has been to create a



The communication boards being delivered to different hospitals in the country

strong network of support for Filipinos with complex communication needs through public awareness campaigns, capacity building of Filipino AAC practitioners, and building relationships and collaborations with various AAC stakeholders. Initiating one project at a time can create ripples that may spread throughout our country, helping us achieve our vision.

The Communication Boards Project was borne out of our desire to help Filipinos with COVID-19 who are confined in hospitals; our small contribution to our society during these very challenging times. Little did we know that this small project was meant to escape our shores and create ripples to other parts of the world.

Photos from: Philippine Association of Speech Pathologists; SLPs of Cebu; SLPs of Davao City; D. Quilantang; Trails Center for Children; Project Shield PH; A. Dannug-De los Santos; J. Fadri; Hirayang Kabataan

SURVIVING THROUGH STORY: UK

COVID-19 personal narratives for children and adults with communication and learning disabilities

by Nicola Grove

www.drnicolagrove.com

“A healthy mind builds proud memories in loving company with specially trusted family and friends, making a good story.” (Colwyn Trevarthen, 2007)



<https://www.youtube.com/watch?v=My0Et66eQEO#survivingthroughstory>

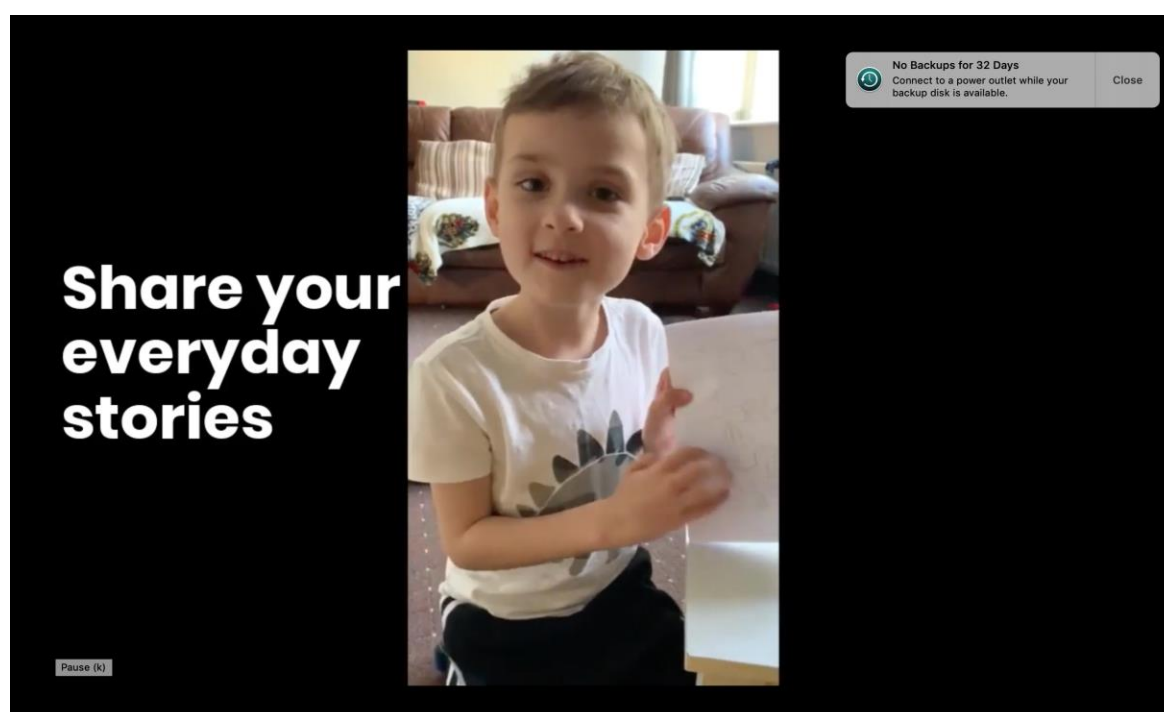
Organizations in the UK have been quick to develop and publish resources to support families of children and adults with special needs and disabilities through this pandemic. At the beginning of April when it became obvious that we were in for the long haul, I started researching what was out there. It was immediately evident that all the available material was factual (some of the best I found are listed below this article). The perceived need was for accessible explanation and information and there is no doubt that this is correct.

However, what we are all talking about and telling each other is not – in the main – how to wash our hands. Instead we are exchanging STORIES of our lives in lockdown. I’m sure all of you, like me, are developing a treasure trove of memories to share about this time – the

comedy, the frustrations, the sadnesses, the small joys. Stories are the way we survive and thrive as human beings. In this time of crisis, building resilience will come through the memories we create together of small everyday joys, sorrows and frustrations – as well as, of course, the big events of life and death that touch us all.

There simply wasn't anywhere that I could find that provided guidance and resources to enable children and adults with SENDs to express what is happening to them. It's noticeable that the voices of people with learning disabilities have been totally absent in the media in the UK, although they are working, suffering, surviving and coping as best they can.

C is a self-advocate who is part of the Social History of Learning Disability network at the Open University in the UK. He has raised this issue constantly since the start of the lockdown. He has two questions: he worries that someone he knows will die from the virus and would like to know how others are dealing with that loss; secondly, his world has narrowed and feels like a prison. We - myself, Flo Hopwood and Katrina Arab, inspirational teachers at Three Ways School in Bath - are working with the Open University and Generate (<https://generate-uk.org>) to explore his idea of creating a newsletter and book of collected stories. Meanwhile, our first step was to create a site for children with SENDs and their families.



Surviving through story

[Surviving through Story](#) provides free videos, downloadable scripts, and information about lives in lockdown, based on the actual experiences of families over the last 6 weeks. We have had fantastic support from partners such as [The Makaton Charity](#), who have provided free line drawings for the core stories; [Pictologue](#), who have created graphic symbol story boards for us; and [Photosymbols](#), who generously gave us a license to download relevant images. Members of [Openstorytellers](#) have made videos for us and shared their ideas and experiences.

Sensory stories

These are scripts that allow people both to tell the stories to the children using multisensory props, and to adapt the stories to their own experience. They are very simple “small” stories of tiny events. An example is our Joe Wicks story - everyone we know in UK is following his exercise routine on television (my fitness instructor son says he is putting him out of work!). But what happens when you try doing this all together in your small flat?



SENSORY STORIES FOR SURVIVING LOCKDOWN

Joe Wicks and me

JOE WICKS AND ME

Resources you will need: Just yourselves and a timer if you want!

Gestures, signs and actions: PE./STRONG HOME, PUSH, BIG, FAST, GOOD, bump, laughing, falling down

Sounds to make: Wow!, uh oh, oops!, Yay!

Feelings in the story: funny, trying hard

Make it your own: Change what furniture you move out of the way, what snack you eat together, what moves Joe Wicks is doing, what causes the relative to fall down, or include any accidental injuries that need looking after..

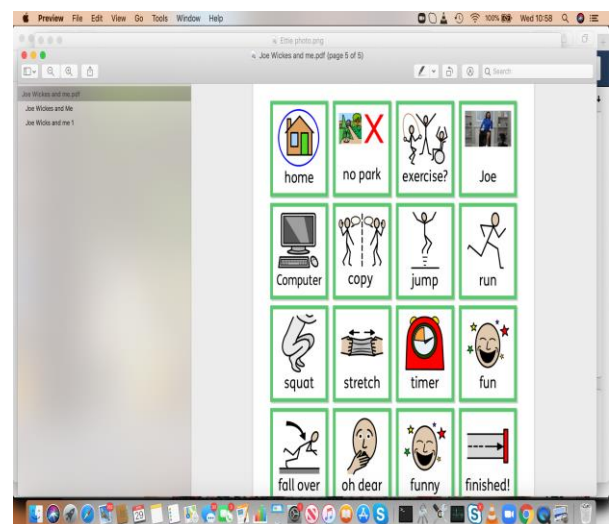
... indicates where the child can most easily join in

Next chapter: Successful moves with Joe Wicks; following other celebrities and what you did; dance party

Adaptations. For children who are not mobile, they can still enjoy being moved, or watching you carry out the actions. Include whatever actions they can manage.

© Arab. Grove & Hopwood 2020

	Joe	SAME		
We have to copy Joe Wicks. Do just the same as him!				
So we did... kicks, stretches... jumps + (for kids in wheelchairs do arm stretches and pumping or whatever physio is appropriate)	Say what you are doing	Copy the actions		
He was so... fast!	Phew!	QUICK		
But it was such... fun.	fun	Clap hands		
Then Joe Wicks said "One minute of squats!" (If child cannot do this they can time you, jump up and down or any other relevant action)		Show the action		Timer - hold timer and set it
Ready... steady... GO!	go	Gesture. Eg. go		
Phew! Keep going keep going keep going!				
Then suddenly...				
We bumped into each other and fell flat on the floor!!!!	bump	Act out, gently bumping		



We've got stories about not going to school, or the park, or swimming (but we can eat chocolate!) baking disasters, as well as specific COVID-19 related issues like Dad self-isolating with the virus, and clapping to celebrate our workers. We've got video examples of how to tell these stories, too.

Our guidelines

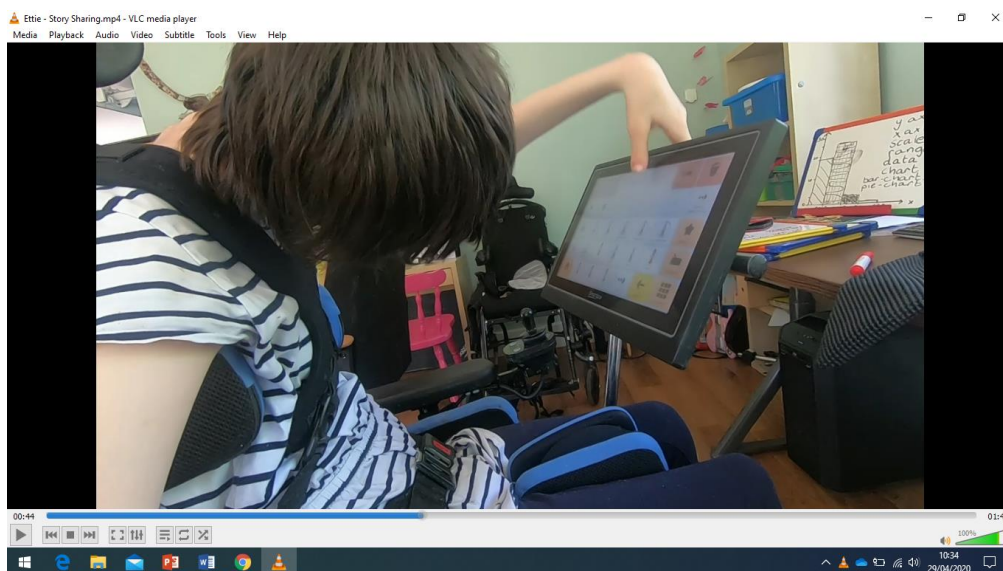
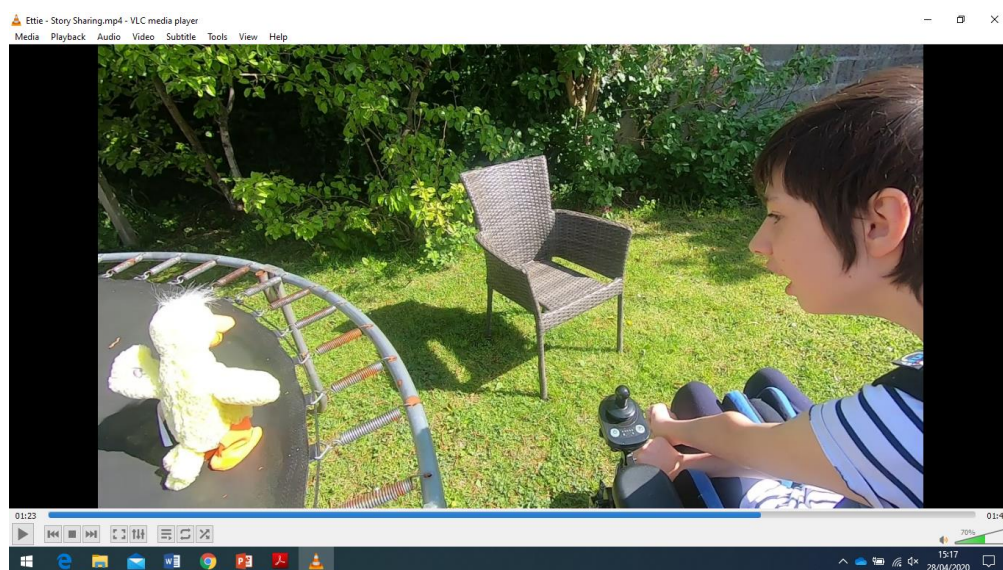
We are drawing on 20 years of practice with Storysharing®. This is a collaborative approach to anecdotal everyday narrative that I developed after noticing how often staff in a day centre told stories ABOUT adults with profound disabilities but never WITH them. In Storysharing® we look for the one thing a person can do to contribute to a small story about their own experience. This might be through a vocalization, a facial expression, a movement, a gesture, or showing an object or a picture, as well as signing and using communication devices. The co-narrator builds the story around this. Flo and Katrina are highly experienced story sharing practitioners you can see in action on the site – and in the film [Guess what Happened to Me](#), made by the charity Openstorytellers to explain and demonstrate the approach. For those of you who would like to get started straightaway, the main message is “don't ask too many questions” as demonstrated by me and my large puppet, Samantha, [on the site](#).



The mum of one of our star story sharers, LG, who has Down syndrome and learning disabilities, explains that when people quite naturally ask L about something that has happened, she will just say “yes,” in order to close the conversation down because she isn’t in control and doesn’t necessarily know what she is expected to say. With Storysharing®, however, she is able to volunteer information and direct the storytelling – and she gets great reactions! Her lockdown story, which we are hoping to post as a film, is about a bike ride with Chihuahuas in the front basket (sorry, you will just have to wait for this one!).

Your stories

We hope that people will want to create and share their own stories. This is already happening as families are sending in their experiences to Flo and Katrina. Again, these are tiny tales. For example, here is E recreating her story of jumping on a trampoline. Note that rather than getting her out of the chair to re-experience, her mother narrates with her what happened by using one of her toys. E then retells the story with her communication device.



Why share stories

Because the sharing of these “small stories” (Bamberg & Georgakopoulou, 2008⁵) is so pervasive and so intuitive, we can find it difficult to explain why the process is so satisfying. In Frome, Somerset, where Openstorytellers is based, there is a new initiative to engage as many people as possible in the town to share their stories of lockdown. The steering group had a go at doing this on Zoom – and when we debriefed, our discussion revolved around the empathy and emotion that was generated between us: *“how simple things have become different for all of us...it makes us want to talk more...I want to say it more than once, this story... story isn’t the same as truth...telling stories is about learning from each other.. especially feelings that are tricky.... N’s story (about frontline nursing trauma) generated an emotional reaction... we are led by the feeling tone....”*

Conclusion

We’ve only just begun to realize the enormity of what is happening and what could change in the world because of it. It is all too easy to overlook the voiceless in our midst. We want our project to enable the inclusion of everyone and to contribute to the recognition of the value of every single human being in our communities. We believe that stories, however small, offer the potential to connect us in a web of shared experience that knows no boundaries and no frontiers.

NOTES

Surviving Through Story is a project run by Katrina Arab, Nicola Grove and Flo Hopwood.

We are in the process of developing a website at survivingthroughstory.wordpress.com

We are also considering hosting some events for families and professionals to show some simple ways of using apps, puppets and film making (from Mascha Legel, obviously!) to enable children and adults to create their own stories of personal experience. Would this be a good idea? Let us know.

Do contact us either via the Facebook site, or email nicolagrovesend@gmail.com

Training in Storysharing® is provided through [Openstorytellers](https://openstorytellers.org)

INFORMATION AND IDEAS

So many great sites out there!

UK: Our favourite COVID-19 information sources are:

<https://booksbeyondwords.co.uk> Picture book explanatory resources

⁵ BAMBERG, M. and GEORGAKOPOULOU, A., 2008, Small stories as a new perspective in narrative and identity analysis. *Text & Talk - An Interdisciplinary Journal of Language, Discourse Communication Studies*, 28, 377–396.

<http://www.speakingspace.co.uk/covid-19-information/> Short films by Alex Kelly with explanations

[Photosymbols](#) provide excellent clear images that feature people with disabilities actively engaged

[The Makaton Charity](#) key word signs for COVID-19

Jo Grace's site has some excellent sensory resources to support families

<http://www.thesensoryprojects.co.uk>

In the USA:

<https://praacticalaac.org> Useful info and advice

<https://riseebooks.wixsite.com/access> Here, Donna Napoli has a wonderful sign language initiative, producing three signed versions of three coronavirus stories for children. They will create e-books and YouTube versions in different sign languages if you send in your versions to them.

Stay well, stay safe, stay positive and.... Keep telling stories!!!

MY BRAZIL TRIP



VIII Congresso Brasileiro de Comunicação Alternativa

December 4 – 7, 2019

PARCEIROS EM DIÁLOGO NA

DIVERSIDADE/Partners in Dialogue on Diversity

UNICAMP e Fundação Síndrome de Down
Campinas

Hello, I am Lateef McLeod, ISAAC LEAD Chair. I had the opportunity to attend, with other members of the ISAAC Executive Board (photo 1), the 2019 ISAAC-Brazil conference that happened in the first week of December in Campinas, Sao Paulo, Brazil. The ISAAC-Brazil conference is biennial, alternating with the main ISAAC conference. This was an amazing, well-run conference and I was happy to attend.



Photo 1: (from left to right) Eliana Moreira (President of ISAAC-Brazil), Renata Varela (Vice-President of ISAAC-Brazil), Lateef McLeod (ISAAC LEAD Chair), Gabriela Berlanga (ISAAC 2020 Conference Co-chair), and Nadia Browning (Chair of the ISAAC Council)

At the conference I was able to present on some of the work I have been doing as ISAAC LEAD Chair (*photo 2, next page*). I also led a seminar (*photos 3 & 4, next page*) where I conversed with other people with AAC from Brazil on the topics of leadership and advocacy. I established many new contacts at the conference of SLPs, other AAC specialists and many Brazilians who use AAC.



Photo 2



Photo 3



Photo 4

Everyone I encountered on the trip was cordial and hospitable, and I felt welcome everywhere I went. I would like to commend ISAAC-Brazil for taking care of my lodgings and transportation for my attendant, Goodluck, and me during our stay in Brazil. In Campinas we stayed at the Casa do Visitante UNICAMP, which had excellent wheelchair accessible accommodations. It was super close to the conference at the university: a very short accessible van ride and we were there. The availability of accessible van transportation was amazing and our driver for the conference provided impeccable service during the time of the conference.

I also had a great time in São Paulo after the conference and I really enjoyed my stay there. I especially liked going the Forró dance club (*photo 5, next page*) and partying there, and also going to the Samba school practice (*photo 6, next page*).



Photo 5



Photo 6

It definitely was an amazing and memorable trip and I had a wonderful time at the conference.

I would like to thank ISAAC-Brazil for inviting me, and especially Nadia Browning, Eliana Cristina Moreira, and Regina Yu for arranging all the logistics for me to come and attend the conference. I cherished the connections that I made with ISAAC-Brazil and I hope to visit again in the not-too-distant future.

FILM-MAKING DURING THE COVID-19 CRISIS: Netherlands & Scotland

by Mascha Legel and Christopher S. Norrie

Com in Beeld & Radboud University Nijmegen, Netherlands

Dundee University, Scotland

Introduction

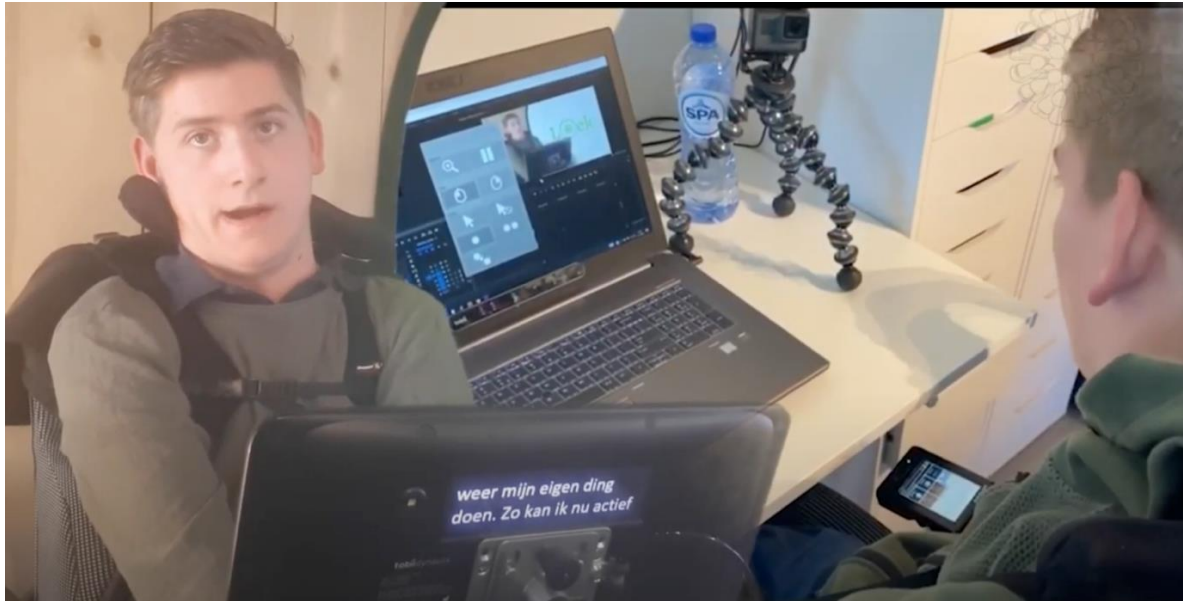
Suddenly we find ourselves socially distancing in a lockdown imposed by governments around the globe to mitigate the COVID-19 pandemic. How can we stay in touch with each other, and make meaningful connections? We make contact with others by sharing our stories and emotions. In such an insecure and potentially lonely crisis situation – unprecedented in modern times – it is essential that we find new ways to share our personal narratives. In our connected modern era, both children and adults have adopted novel methods for telling their stories using social media on platforms such as Facebook, Twitter, and Instagram. Important ingredients afforded by these kinds of digital technologies are audio-visual (AV) media such as pictures and video. These can be leveraged to provide scaffolding, in the form of context and detail, to build personal stories around. Such augmentations can bring vivid colour to a flower, life and movement to a flock of birds on the wing, or the startling splat of a pancake as it drops unexpectedly to the floor. With the availability and popularity of AV technologies such as smartphones, tablet computers and increasingly affordable assistive technology devices and apps, nearly everyone now has the chance to collect and utilise these enriching story elements.

Project

Based on the principles of Film as Observable Communication (FaOC), our non-profit foundation started a YouTube channel called “Cam on Wheels-Corona-Time” in which children and young adults, both with and without a disability, create and edit personal vlogs during their home isolation.



Film and storytelling



Film and editing

Vloggers who need assistance in the filming, editing or technical accessibility of their devices are coached and assisted by the Cam on Wheels crew.



Cam on wheels assisting crew



Editing

Cam on Wheels is a film production studio based in Rotterdam where young people, with and without disabilities, make professional audio-visual media productions and give language-film-edit lessons at a special education school on a daily basis.

This education program – which consists of the teaching method *My Film, My Story* – was developed to assist not only children and young people with complex communication needs (CCN), but also to support teachers, speech language therapists, and parents in creating their own films as a tool for story sharing and language development.

The teaching method is still in development and is based upon a collaboration between Radboud University Nijmegen, The Netherlands, The University of Dundee, Scotland, and Com in Beeld/Cam on Wheels.

Method

In the Cam on Wheels-Corona-Vlog project, the use of joint expertise in developing AV media productions and the FaOC teaching method *My Film, My Story* form an effective and fun combination to create and share stories during home isolation.



Filming fun activity

Stories, after all, are everywhere – manifesting in everyday events such as baking a cake, trying out a new soup recipe, inventing a game, playing music, decorating your room, or acting out a play. Story sharing is pivotal in making ourselves *visible*. If speaking or writing words represents a challenge for an individual with a communication impairment, images can be used to augment or offer alternative ways of conveying meaning. With self-created images in combination with all other modes of (AAC) communication, the person with CCN is the director of their own film and therefore their own story. Our research suggests that this process of agency can promote individual independence, with a significant boost in self-confidence for participants.



Making music

Conclusion

Perhaps even more important than the end product (i.e. “the Vlog”) is the collaborative element, with opportunities for communication incorporating a range of AAC strategies and technologies, and creative story making and sharing between the filmmakers of diverse abilities. Both Cam on Wheels film students and participants are enthusiastic about our innovative project. Moreover, it helps them all to feel less isolated and alone during the ongoing coronavirus lockdown. In conclusion, this collaborative process allows all the contributors to submit beautiful personal stories from their own unique perspective - thereby enriching their own lives and those of the people around them.

If you are interested to make your own Vlogs, and need assistance with filming or editing, you can make contact with the Cam on Wheels crew. All Vlogs are welcome on the Cam-on-Wheels-Corona-Time Vlog Channel. We look forward to your stories.

For an impression, just have a look at the Cam on Wheels-in-Corona vlog channel:

<https://camonwheels.nl/gallery-3/>

<https://www.facebook.com/groups/538238787051758>

<https://www.youtube.com/watch?v=uumwPowHXhM>

More info:

www.camonwheels.nl/ www.cominbeeld.nl

<https://www.beweginginzicht.nl/en/projects/perception/visualisatie>

A WELCOME RECEPTION TO AAC IN A SMALL VILLAGE: UK & Republic of Moldova

by Sharon Rose UK Speech and Language Therapist

My initial visit to the Republic of Moldova was in May 2016 with Zoe Wilkinson (speech and language therapist) and Di Acaster (Assistant Director of [Breadline Charity](#)). It was my first visit to a developing country. The main language in the village I was staying was Romanian, with some people also speaking Russian. We had an interpreter who came to most visits with us. Zoe had previously visited with another charity to deliver training to church communities to support them to provide an inclusive environment for people with disabilities. The Hope Church in Dancu, Republic of Moldova, had started a group for children with disabilities and communication difficulties. They were keen to include these children more and develop their skills and knowledge. Disability in the Republic of Moldova has been relatively hidden until recently with people with disabilities staying at home. Things are changing now. Zoe invited me on this visit to work with her and use some of our skills as speech and language therapists.

So, I found myself in the village of Dancu, surrounded by a wonderful group of people whose greatest desire was to support children and adults with disabilities or communication difficulties to be included in their community. The “Hope Club” not only provided an opportunity for the children to socialize but also a place to develop their skills as many of these children did not go to school. The children and teenagers attending the Hope Club came from a number of villages in the region and ranged in their age and their communication skills and methods. The group included children and teenagers with autism, cerebral palsy, syndromes (often undiagnosed), and significant visual impairment. During the Hope Club session, a range of activities were set out and we worked with the children and teenagers. One of the young people who had cerebral palsy clearly had good understanding, the physical skills to point accurately, and a great desire to communicate. We had a couple of Go Talks, which Di had previously sent out, a few communication charts and some pages from a communication book, which we had brought with us. We introduced a simple drawing and colouring task. The young person communicated using the communication chart by pointing to the colours and shapes they wanted. We then set up the *Go Talk* so they could engage in a simple social exchange, “How are you?” “I’m good.” The celebrations and smiles we saw that day when this young person’s communication was unleashed were amazing – and that was just from the helpers. The smile from the young person was HUGE!!!



A young person communicating with Di Acaster using a *Go Talk*

During our time in Moldova, we worked with another child with profound and multiple learning disabilities who used their face and body to communicate and we talked about how the team and the child's family could develop their communication through sensory experiences, on- body signing and programs such as [Tacpac](#). "Tacpac draws together touch and music to create a structured half hour sensory communication between two people."

The team there have a holistic approach and the group provided a space to meet, an opportunity for parents to mutually support each other, a little respite and a place of acceptance. The team didn't stop there though and were advocating for the families and sharing their knowledge and skills in the local schools. This meant that we could also go and offer some informal training on how to use the local language, Romanian, version of [Widgit's](#) Symbol Software *Communicate In Print 2* which Di had sourced for them.



Informal training so the team and school staff could use *Communicate in Print 2*

In Summer 2017 I returned to Dancu and spent two months with the wonderful team there. I was able to join them on visits to families and children not only in Dancu but in other villages across the region to support people with disabilities. In my first week, we visited a young person who had a diagnosis of diplegia who was desperate to communicate, but had mainly two sounds – one for yes and one for no. The next time we visited we took a communication chart with us. After showing the team how to use the chart, they quickly used it to model asking and answering questions about their own lives. The young person quickly responded and was so happy to tell us their favourite drink and things they liked to do. We were able to invite the young person to the summer camp that the church put on for children and teenagers in the Hope club. We then developed communication charts which enabled them to participate in the different activities, discussions and the quiz we had about the story at the end of each morning.



Communication charts used within the summer camps

It also gave us the opportunity to put together a very basic communication book to facilitate their communication using the *Communicate In Print 2* software. One of the team commented, “Now I don’t have to guess what they want, they can tell me.” Making the communication book was an opportunity to train a member of the team to use the software. Although we had delivered training back in 2016, the team no longer had access to the laptop with the software on. We transferred the software onto an accessible computer – if you don’t use the software, you lose your confidence in using it. Making the communication book proved a useful refresher! We also used the software to create a visual timetable of the day’s activities which the team used to help the children and teenagers transition between activities.



Vadim, one of the team, communicating with the young person using the communication book (*on the left*)

In the village there were children who needed objects of reference, on- body signing, signing, communication charts and Picture Exchange Communication System. Providing informal training about AAC and communication alongside visiting families and children with the team proved effective. The team were more aware of different types of AAC and were then seeing opportunities to put these in place and develop the communication of children we visited. However, I do still remember as we set off to see one child a member of the team saying to me “They don’t do anything, I don’t know what you will do Sharon....” I gave them a little confused look and they changed their mind quickly, “Ah, of course we could use objects of reference or on -body signing.”

We visited another boy and introduced a couple of basic signs. I was very excited when we went back the next week and he had signed ‘sweet’ to his Mum as she prepared to go to the shop – functional communication right there! We had conversations about why ‘one method does not fit all’ and that each person will need AAC appropriate for them.

There is a lot of resetting of people’s thought processes in terms of communication and what this constitutes – a whole culture , but what I love about the work in Moldova is that when you engage with the right people and can show the impact, there is no stopping them! One of the team (Tania) decided to train as a speech and language therapist in Autumn 2017 and she invited me to join a lecture and share experiences with the speech and language therapy students when I visited them.



Sharon Rose sharing experiences at a University in Chişinău



Sharon Rose (*left*) with Tania (*right*) who is studying speech and language therapy

I returned to Dancu in October 2019, planning to spend a year with the team there but unfortunately, I had to return to the UK at the end of March this year due to the coronavirus. Despite this I am continuing to stay in touch with the team through texts, emails and WhatsApp calls. As is the case across the world, the families and children I have been working with are in isolation and so it is difficult to be in touch with them at the moment as not all of them have the internet. I am continuing to develop resources that may be useful for the children and young people in the future. I am mainly doing this by producing a draft form, taking a photo and sending it to them for their comments to ensure that the language used is correct or by sending resources for translation to the translator that we use. I was able to produce a personalized social story about isolation using *Communicate In Print 2* for one young boy with autism and sent this to his family via email having converted the file into a PDF.

During the time I was in Moldova, I was going into three schools, a nursery and a day centre in the region regularly. I was also involved in the Hope Club where we had begun to incorporate “Bucket time” from [Attention Autism](#) (see *Attention Autism – Therapy Ideas Live video, starting at three-minute mark*) and interactive stories.



“Bucket time” at Hope Club with Sharon Rose



The end of an interactive story at the Hope Club

I cannot fault the welcome I received from staff or their openness to me despite the ideas I introduce being new and different. AAC is not something used routinely by the speech and language therapists I have met so far. My understanding is that every school in Moldova has a “logoped” (speech therapist) and their main focus is to improve children’s speech. Recently, I met with a therapist who told me that using signs or symbols would slow the progress of the child’s speech down and another professional who works with children with cochlear implants also told me that using signing would hinder progress. For parents, AAC is not commonplace but some forms of AAC communication are more acceptable than others. Tania just has her thesis to write and will then have finished her studies. She is amazing at thinking about different ways children might communicate and is able to explain this clearly to parents and

other professionals alike. The director of the nursery who has been working with children with communication difficulties for years now is a real advocate for thinking outside the usual “speech route.” On the International Day for People with Disabilities in December I was invited to do some sessions in the local school with children from 7 - 16 years. I split them into groups and gave them the task of getting a specific message across without speaking. They were encouraged to use gesture, facial expression, drawing, or a communication chart. Some of the students asked really good questions about how a person who can’t hear or speak might communicate. It was exciting to see and hear their views on disability and communication difficulties – and that people should be included. The church is also hoping to build an accessible extension that will have a specific space for them to continue the work they are doing.

I am loving the opportunity of collaborating with local people, to make changes setting by setting and increasing awareness and use of AAC so that all forms of AAC become more acceptable and a valid means of communication.

REPORT ON DONATION OF COMMUNICATION DEVICES FOR LEARNERS WITH COMMUNICATION NEEDS IN GHANA, BY SMARTBOX ASSISTIVE TECHNOLOGY: Ghana

by Belinda Bukari, Unit Head, Education for Learners with Intellectual and Developmental Disabilities

In March 2019, the Chair for ISAAC BUILD committee nominated Ghana to be the recipient of the 2019 donation of [SmartBox](#) communication devices for persons with communication difficulties. Dorothy Fraser's nomination was based on the work done with Belinda Bukari, the Unit head for Education for the intellectually and developmentally disabled at the Special Education Division through the Central Coast Children's Foundation and Teacher's College, Columbia University, New York, on Augmentation and Alternative Communication to improve the communication needs of learners with communication difficulties among the Unit Schools across Ghana.

This donation was by SmartBox, a non- governmental organization based in the UK. The decision to apply for the donation was to be made by Ghana and upon reading through the project plan and conditions, Ghana applied for the devices. An interview via Skype was convened between the Rep from the Special Education Division, Ghana Education Service in Charge of Education for Learners with Intellectual and Developmental Disabilities; Dorothy Fraser, Chair of ISAAC BUILD; Franklin Smith, Executive Director, ISAAC; Stephen Hyde, Head of Service, SmartBox. Neil Hanson, Lindsay Milgram, and Catherine J. Crowley and the team approved of Ghana as the recipient of the devices upon a decision made after the interview. Of course, Sarah Blackstone of the Central Coast Children's Foundation also gave her support for Ghana to receive the devices.

The Deputy Director-General in charge of management Services wrote to SmartBox about the preparedness of the service to receive the devices. He stated the fact that the success of Ghana's implementation of Inclusive Education depends on such supports from partners such as SmartBox.

Ghana Education Service received the devices in July 2019. The Unit Head of Education for Learners with Intellectual and Development Disabilities selected six (6) students in the special units and mainstream schools as beneficiaries of the devices. This was done through the heads of schools of the selected students through psychological and needs assessment reports of the students.

A training session was scheduled to take place in January, 2020 after the team from Teacher's College, Columbia University, New York, completed their annual professional development

retreat for teachers from the 23 special units on Augmentative and Alternative Communication on Literacy Skills.

On January 10, 2020, the training of students, parents and teachers on the use of the communication devices took place at the Director-General's Conference room at the Ghana Education Service. The training was led by Joanna Hokenson, Carol Hammer, and some graduate students, all from Teacher's College, Columbia University. The training was basically on how the Grid 3 software works to improve the communication needs of the beneficiary students and the step-by-step instruction of how to use the communication devices.

In a short ceremony, the Deputy Director General in charge of Management Services at the Ghana Education Service, Mr. Anthony Boateng (Esq.), presented the Devices to the Director, Special Education Division.

The Deputy Director General thanked SmartBox for their kind donation and gave the assurance that the devices will be put to good use.



The Deputy Director General, Director Special Education Division and the team from Columbia University, together with teachers, parents and pupils.



The Director for Special Education tasked parents to ensure the safety of the devices and use the skills acquired during the training to help the children at home to complement the effort of the teachers. She expressed her appreciation to Cate Crowley and her team, Central Coast Children's Foundation, and the Chair of ISAAC BUILD, with sincerest gratitude to SmartBox for the generous donation. Also present at the training were the Financial Controller and the Director General's Secretary of the Ghana Education Service.



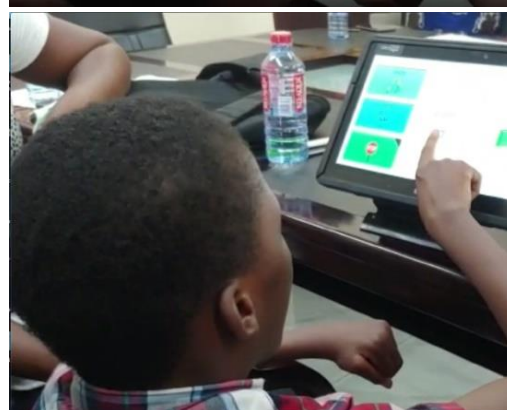
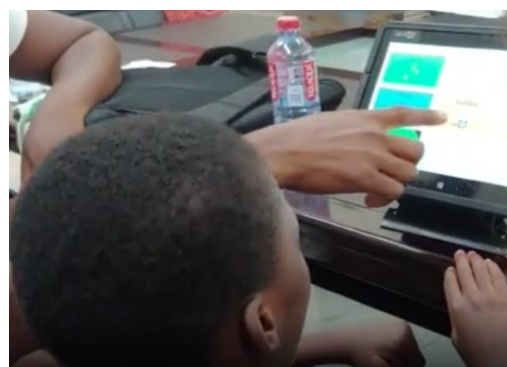
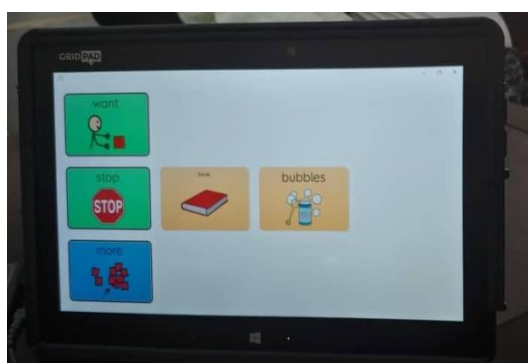
Belinda, Joanna, Carol, the Director for Special Education and Deputy Director General with some students from Teachers College Colombia University



A student receiving a device and their parent's joy



A beneficiary with his father and a teacher



The Special Education Division, the management of Ghana Education Service, and parents of beneficiary students are very grateful to you all – most especially SMARTBOX.

CONFERENCE NEWS

ISAAC Conference 2020 – postponed



Dear ISAAC Supporters,

The ISAAC Executive Board decided to postpone Conference 2020 until July 31st through August 5th, 2021, in response to the COVID-19 pandemic. The well-being of all those who travel to our biennial conferences, in particular people who use AAC, their families and personal support networks, is and always will be our priority.

Questions and answers about the conference postponement are answered online [here](#), in both English and Spanish. You can access our evolving list of AAC and COVID-19 resources on the [ISAAC website](#).

We look forward to gathering together next year in Cancún, México, to enjoy the same dynamic educational, cultural, and social programs you have come to expect from ISAAC conferences.

For now, as we work together virtually during the COVID-19 pandemic, ISAAC International leadership and staff are committed to doing all that we can to support the global AAC community by providing online content and opportunities for our members worldwide. We are busy developing webinars, blog posts, PWUAAC online chats, and much more. We plan on announcing new opportunities in the coming weeks and months.

Best wishes from all of us at ISAAC for your good health and safety!

Meredith Allan
President, ISAAC

Franklin Smith
Executive Director, ISAAC

RESOURCES

General Resources

[Ways to Communicate](#) Communication is a two-way process: Clearly explained in this YouTube video.

[Surviving through Story](#) COVID-19 personal story resources on Facebook: Video of a girl telling her story of hospitalization with brilliant story-sharing support from a teacher

Healthcare Resources

Providing links to websites with information and material for patients, professionals, communication partners, families, and friends to support their communication during the COVID-19 crisis, and relevant resources for use in other medical situations: for people who permanently require communication support (PWUAAC) and also for those temporarily unable to use their regular means of communication.

Note: Material is available for free download, in many languages:

www.patientprovidercommunication.org

<https://www.patientprovidercommunication.org/supporting-communication-covid-19.htm>

ISAAC-NF (Netherlands and Flanders Chapter) <http://www.isaac-nf.nl/covid-19-aac>

ISAAC-Brazil Chapter, together with the Federal University from Rio Grande do Sul (UFRGS), has created communication boards in many languages to support healthcare teams and people with complex communication needs during COVID-19. All free and available at the [ISAAC-Brazil website](#) and the [UFRGS website](#). The ISAAC-Brazil website includes additional material to support people during this pandemic.

<https://keycommaac.wordpress.com/covid-19-resources-for-health-care-setttings/>

<https://keycommaac.wordpress.com/> with sections for families, users, and professionals

[Blissymbolics Communication International](#) Useful words for talking about the Corona pandemic

[Communication Therapy International COVID-19](#) Please see our Resources page for links to easy to read, translated, and AAC resources for supporting people with communication disabilities worldwide during the pandemic.

Resources (including material related to COVID-19 pandemic and lockdown)

Social Story explaining why a child can't go to school during the COVID-19 pandemic and Information to support explaining about the COVID 19 pandemic in Portuguese:

<https://www.grupoadastra.com.br/csa-e-coronavirus>

<https://www.gov.uk/government/publications/coronavirus-covid-19-online-education-resources/coronavirus-covid-19-list-of-online-education-resources-for-home-education>

Including special educational needs and disabilities (SEND)

www.janefarrall.com

<https://akidsbookabout.com/pages/covid-19>

[AAC in Telepractice by Rachel Madel](#) on YouTube

www.callscotland.org.uk

<https://praacticalaac.org>

www.ipaworld.com

*IPA's purpose is to protect, preserve and promote children's right to *play* as a fundamental human right, as enshrined in article 31 of the United Nations Convention on the Rights of the Child. IPA is concerned about the *play* rights of children experiencing difficult circumstances or challenging environments.*

<https://www.playscotland.org/newly-published-ipa-play-in-crisis-support-for-parents-and-carers>

Other Resources

www.easy-read-online.co.uk

<https://accesseasyenglish.com.au/>

www.pathstoliteracy.org

Cortical Visual Impairment (CVI) -friendly videos, which are available for free on YouTube.

www.connectability.ca/visual-engines

www.totalcommunication.org

Autism

Sensory chart: householdquotes.co.uk/sensory-overload

<https://www.aspiecomic.com/missing-links.html>

Video on how to best communicate with an individual with Autism: [Autism: See The Potential](#)

Movies

Maudie [https://en.wikipedia.org/wiki/Maudie_\(film\)](https://en.wikipedia.org/wiki/Maudie_(film))

Crip Camp: a disability revolution [CRIP CAMP: A DISABILITY REVOLUTION | Official Trailer | Netflix | Documentary](#)

Miracle in Cell No. 7 - [Miracle in Cell No. 7 \(Original Version\) English Subtitle](#)

Book

"Funny, You Don't Look Autistic" is a memoir written by Michael McCreary. Michael is a Canadian writer and comedian in the Autism Spectrum Disorder (ASD). He writes in a very funny and reflective way about how he lives in the Spectrum.

<https://www.amazon.ca/Funny-You-Dont-Look-Autistic/dp/1773212575>

Ted Talk

[Listen, Acknowledge, Include](#) | Glenda Watson-Hyatt | TEDxSFU.

FAREWELL NOTE

Thank you to everyone who contributed information and all of you who read CSWN, our global newsletter!

Our next edition will be published in December 2020. We would love to hear your news.

Please submit your article and/or news by November to nadiabrowning@gmail.com and dotfraser2@gmail.com.

The format is Calibri Font 12 with a guideline of approximately 4 pages and 5 photos.

We look forward to hearing from you!

Stay safe,

Nadia and Dorothy