

TREADING THE WAY TOGETHER IN THE ALTERNATIVE COMMUNICATION: LIFE STORY

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Abstract

This article reports several passages in my life. I introduce myself: a person with cerebral palsy who use alternative communication systems. Among these passages, I highlight the admission to the especial education school (APAE), with eight months old, where I also attended kindergarten I and II. After that, I was literate in a municipal school, and finally, I joined in the Federal University of Rio Grande do Norte, where I major in Language - Portuguese. In this trajectory, I was assisted by many people and I used various adaptations, resources and equipment to carry out my motor activities, such as a motorized wheelchair, head pointer to use a tablet, one switch mouse. I end my testimony by thanking God for everything that has worked out in my life, and, as I say, I demonstrate the beauty of my “differences” and the greatness of my “limits”.

Keywords: Augmentative and Alternative Communication. Life Story. Cerebral Palsy. Adaptations.

I am Jamilla, the only daughter of Frassinetti and Josebias. I am 26 years old, I was born in Currais Novos / RN.

I have cerebral palsy due to a medical error at birth, which affected my movements and the speech, which is why I am describing my story. But this was not an excuse or an obstacle for preventing me from fulfilling my dreams.

From a very early age I felt the challenges that life imposed on me; but I have been conquering each of them with great perseverance. I always say that God was wonderful to me, even before my coming to the world, for sending me to my mother, who is everything in my life!

If today I am here, telling you a little about myself, she is the one who teaches me to never give up on my dreams, even with my “limitations.” At 8 months of age, I was referred to APAE, for medical advice, because I needed early stimulation; there, I kept developing, meeting the expectations of the teachers who noticed my progress in learning the letters. I started kindergarten I and II there. Due to my advances and my will power to learn, the team instructed my mother to enroll me in a daycare center, starting my school life at the age of six. I learned to read in the municipal daycare center Ednólia Melo. The adaptation was a bit difficult because I was not used to be without my mother, so I cried a lot. But today, I thank her for believing in me.

I am a patient at Sarah Kubitschek Hospital in Brasilia. In this hospital, I have been in the rehabilitating program since I was four. There, I've had and still have follow-up with doctors and with augmentative and alternative communication, several attempts were made and experiments with equipment to use the computer. Every time I return, every year, I train and bring new adaptations to improve my writing on the computer.

I've had so many adaptations ... Me? I'm always ready and willing. From the beginning, I used the one switch mouse with a chin pointer and a keyboard with a scan. After day-to-day use, it was slow, and I wanted to move forward; I began to train with a rod in the head with a pointer on the chin, but I did not adapt because I got really tired; they changed to the keyboard with a keyguard and a five-button mouse. This one I used a lot, and my left hand on the regular keyboard without a keyguard due to my motor difficulty. They decided to explore my left hand. They made an adaptation for the finger, but my involuntary movements did not help. So, they trained until they got to a pointer on the left wrist. Finally, we got to what really worked out and until today, with this adaptation, I use the mouse set to the keyboard, I do everything, I even draw. In fact, there are two pointers: one for the computer and another one for the tablet.

The team suggests new ways to improve, and I accept, challenging myself. I have always been and I am very well welcomed wherever I go. In these comings and goings to Brasília, I had the pleasure and happiness to meet two families, who are Arimá Cruz and Vivania Brandão. They are families of enlightened people who go out of their way to help me, whether at school or anywhere. Despite my difficulty in communicating, I make friends easily and I really like it, and this has always made my life easier. My classmates and teachers have always helped with the games and activities (to write in the classroom, because I do not have motor coordination). And it must be so! Being treated normally, therefore, I have never felt "different" because I am "equal" to everyone. I have this privilege, because those around me treat me normally, whether by family, colleagues or friends, so I did not hesitate to take various adventures such as paragliding, trails in Pico do Totoró / RN and riding a tricycle. With the passing of the years, things have improved, difficulties have diminished and I have gained another independence: walking on the streets of the city in my motorized wheelchair, thanks to the initiative of my friends Fátima Souza and Jean Souza who made a campaign, and they were able to fulfill one more of my dreams, as I say: I just need friends and adaptations.

My childhood was shared by cousins with many games, tricks, discoveries and especially much love. We've been together since I was little, I have two godmothers, one is called Dannila. She has helped to take care of me since my birth and has been with me through my school life by always taking me to class. She has always encouraged me, and

today she continues to support me in what I want. The other one is called Marcioneide, she has always lived with me, she knows my tastes, we have a great affection for each other, and I also know that I can count on her when necessary, as she has already proved this by staying with me and taking care of me when my mother couldn't.

I have only my paternal grandmother, Nair, next to me. She cares about my daring adventures, but she gives me the strength to move on.

My Aunt Nanci, very special and essential in my life, as much as my mother's sisters. They are all my references and I love them. These are the reasons that made me strong, so I never felt "different." I speak "different" in the sense of "limitations" that do not stop me from doing what I want. After all, nobody is the same.

After my inclusion in the day care, I went to a regular school: Ausônio Araújo Municipal School, where I got a wonderful teacher to teach me! I can say: she did justice to the word inclusion. I studied since first and second grade. I remember this time a lot ... The principal collaborated a lot! At that time there were no such facilities as today: such as school transportation. When I had activities outside of school, she, the teacher and my classmates took me without any complaints.

We left the school on foot, my teacher and my friends took me, pushing the wheelchair, which was already adapted with a belt, and with that, I felt safe to face bumpy streets, up and down slopes. Often, when it rained, the muds were deep, because some streets had no pavement. In this way, they made me happy as they never left me behind and I was able to participate in the moments of studies and games.

From then on, my studies have been a success! I've had excellent teachers! I've learned a lot. At first it was always that expectation ... Then I got used to it. I cannot fail to highlight one of my reasons of proud: my school has always been the Public School. From nursery to high school. I never wanted to stop there, I was dreaming about graduation.

When I tried my first vestibular (university entrance test), I was so anxious! It's said "to be normal", everyone gets like that and I thought I was the only one. I was the first student to take adapted vestibular tests by the Federal University of Rio Grande do Norte (UFRN). I was not approved. Even so, I kept trying, until I got an opening at UFRN, a quality institution. After many vestibulares, I was finally able to pass the Portuguese - Language course (Distance Education).

(Describe to the reader how the adaptations to the college entrance examination were. This is the journal's theme, about adapted motor activities)

I remember it like it was today. On the day of the test result, my mother and I were looking at the list of approved students ... When we saw my name, it was one of the greatest joys of our lives! My mother ran, out of happiness! People always asked

questions such as – how about when she gets to college? We did not worry about that much because I would only know when it happened. And the questions? Now you have answers. There was no need for me to adapt to university, but we were adapting every day and I was very welcomed by all University staff as well and by CAENE - Commission for Support to Students with Special Educational Needs (2017). I've had this support from the beginning of my course. The staff is there for me for whatever I need. I had my interview with CAENE with total independence, using the tablet with a voice system, Grid Player, Sarah's augmentative and alternative communication.

I want to take opportunity and thank CAENE for the care and availability of the team during the four years (it will now be four years, at the end of my last term). So, just as my entire school career, at university it was no different. I had difficulties in the pace of homework, readings, tests. And I was fortunate to have an enlightened person to be the face-to-face tutor, Elba Alves. I can say: it was a great challenge for me as well as for her. One of the things I am grateful for is that she pushed me when it was necessary. And for showing me that I am capable to put my ideas, thoughts and opinions into practice. I always say: she clarifies my mind with her guidance. But, unfortunately, I will not finish the course with the same guidance, because as there have been many cuts of funds, she was removed from the tutoring. Her departure was a fresh start for me. Nothing personal about other tutors, I say that, simply because we are on a journey of conquest and autonomy, I understand ourselves better.

I often say: it is not me who have to adapt to the new challenges, but it's the challenges that adapt to my needs. It has happened this way so far, even my college entrance and on this course.

At the age of twenty-six, I am fulfilling one of my dreams, that of completing the last term of the course of Languages - Portuguese, at Federal University of Rio Grande do Norte. So, if God allows me, I intend to go much further. I haven't finished my course yet, but I'm already thinking about what I'm going to do next year. I'm in doubt, if I try my graduate degree or if I prepare for public jobs ...

I want to take another step ... And I intend to enter the labor market, not only for the right to compulsory vacancies for people with disabilities, but for my qualification and knowledge in the area, in which I will be able to act. That way I will feel fulfilled in knowing that all my effort was worth it!

I end my testimony thanking God for everything that has worked out now and in my life. To my parents, my family, teachers and friends for being by my side. I apologize to those whose names were not mentioned, but they are all remembered and have a special place in my heart. I am proud to be a part of this Conference at the Federal University of Rio Grande do Norte¹.

¹ This text was presented orally during the Alternative Communication Conference, promoted by

And to say: I show the beauty of my “differences” and the greatness of my “limits”.

I quote a poem by Fernando Pessoa, which I identify myself a lot, which shows my will to win.

Impossible Dream (our translation)

Fernando Pessoa

I have a kind of duty,
duty to dream, duty to dream
to always dream,
because being more than
a spectator of myself,
I have to have the best show I can.

And so I build myself to gold and silks,
in presumed rooms, I invent the stage, the scenery,
to live my dream
between soft lights
and invisible music.

Impossible dream

To dream another impossible dream
To fight when it's easy to give in
To beat the invincible enemy
To deny when the rule is to sell
Suffering the relentless torture
To break the invasive prison
To fly to a probable limit
Touching the inaccessible floor

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It's my law, it's my question.
To turn this world, to stick to this ground
I do not mind knowing
If it's too terrible
How many wars I will have to win
For a little peace
And tomorrow if this ground that I kissed
For my bed and forgiveness
I'll know it's worth it.
To rave and die of passion
And so, whatever it is
Endless affliction will come to an end
And the world will see a flower
Sprout from the impossible ground “.
Fernando Pessoa.

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