



Learn from my Mistakes

*12 years of figuring out how to support
my Autistic son*

Dr Nida Taufiq

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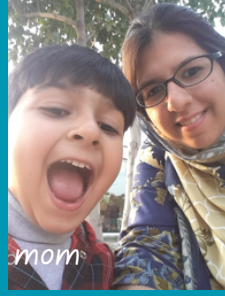
We have rebranded
"Managing Autism with Mothers and Aunties"
is now
"Mindfully Supporting Autistics with Mothers
and Aunties"

About Me

Dr Nida
Taufiq



Pediatrician



Autism mom



Ex Major



Certified
Autism
Specialist



Certified
Health
Professions
Educator



Founder of
MAMA

First, a little about me.

I am Dr Nida Taufiq. I am a Pediatrician. I served in Pakistan Army for 8.5 years. I did graduate studies in Autism Spectrum Disorder from the Department of Special Education, the University of Kansas, USA. I have also done a certificate in Health Professions Education from NUMS, Pakistan.

I am the founder of a company by the name of "MAMA". Managing Autism with Mothers and Aunties; where we believe that through collaboration and by following the child's lead we can manage/tackle the challenges that accompany a diagnosis of Autism whilst celebrating and marveling at the unique strengths that each child possesses.

But most importantly. The thing that really defines me is being Musa's mom. Musa is my 12 years old son who is Autistic. Those of you who follow me on Instagram would know him quite well.



Disclaimer

Most of the information provided is based on scientific/evidence-based practices but not all. Some of the tips provided are based on my experiences as a parent and my personal beliefs that have been shaped by my religious and cultural background. I am on a journey of perpetual learning and I might forgo some of my current suggestions in the future.

Yup, mindsets change, beliefs change.
I used to be an advocate for compliance based therapies
but not anymore.



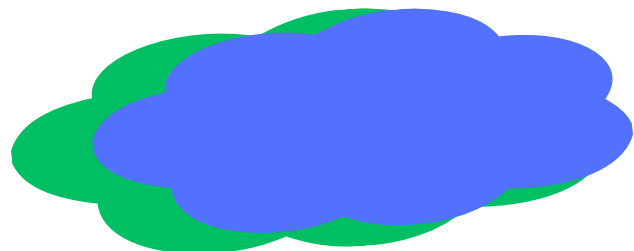


Sequence



12 Years 12 Mistakes

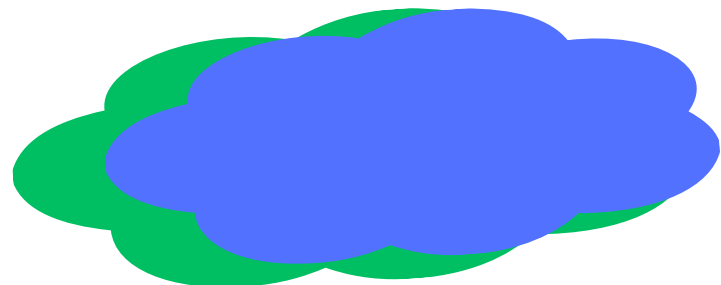
- Our Journey
- Mistake # 1 : Diagnosis/Evaluation
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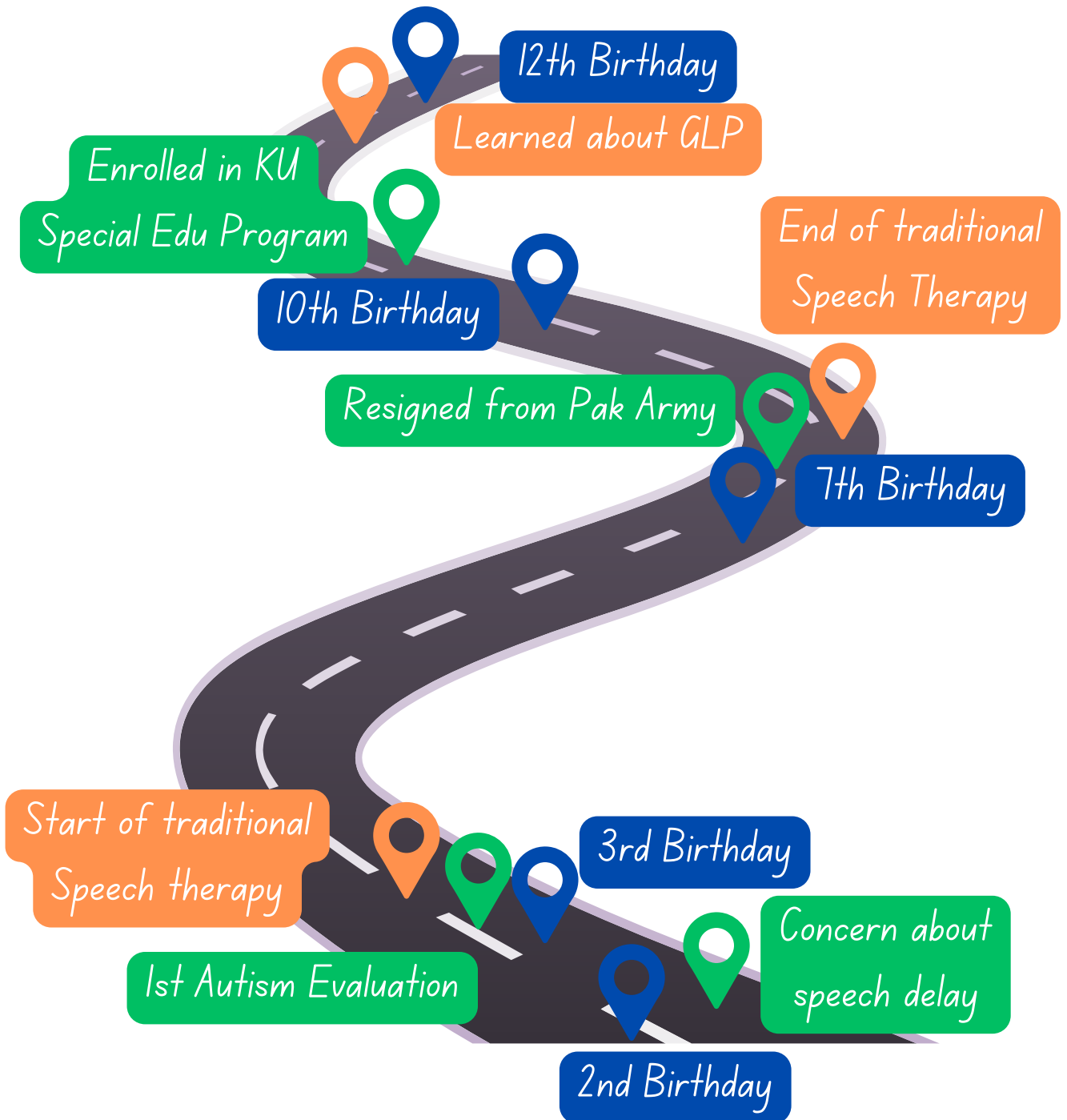
Our Journey



Now, I am going to give you a quick overview of the major milestones of our journey so that you can get an idea of where most of the mistakes occurred and where things started to change for the better. This would serve as a reminder to those of you who are reading this that it is never too late to learn or make amends.



Our Journey (cont.)





Our Journey (cont.)

Shortly after Musa's second birthday I started to really get concerned about his speech delay.

His first, somewhat proper Autism evaluation took place after he turned 3 years old. It was followed shortly by Musa starting ABA style speech therapy.

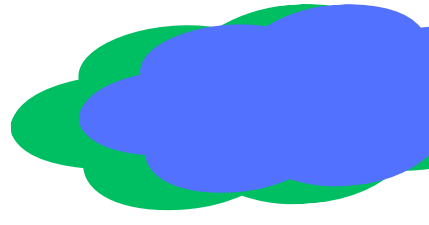
The 4 years that Musa was going for speech therapy were the same 4 years that me and my husband were doing our specialty training. That is, I was busy being a Pediatric Resident and he was training to be a Radiologist. So these were super super stressful busy years.

Near the end of my training I resigned from Pakistan Army. I passed my exit exam that is FCPS part 2. After that is really when I started to put Musa's learning first.

But I was lost. I didn't know how to proceed. الحمد لله
I stumbled upon KU's special education program.
So most of Musa's progress occurred after he turned 10.

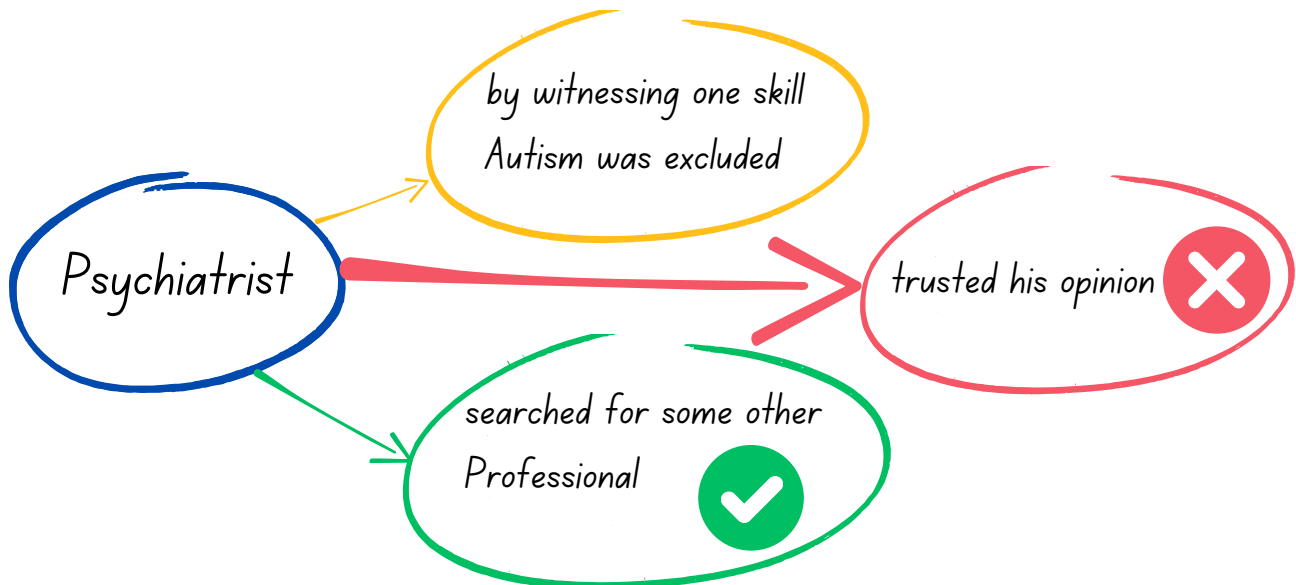
Last year I took a deep dive into the Natural Language Acquisition framework for Gestalt Language Processors.

With that a snapshot of our journey till now is complete. Musa turned 12 الحمد لله in November 2023.



Mistake # 1

Diagnosis/Evaluation



Now, coming to Mistake # 1 which is about Musa's Autism evaluation.

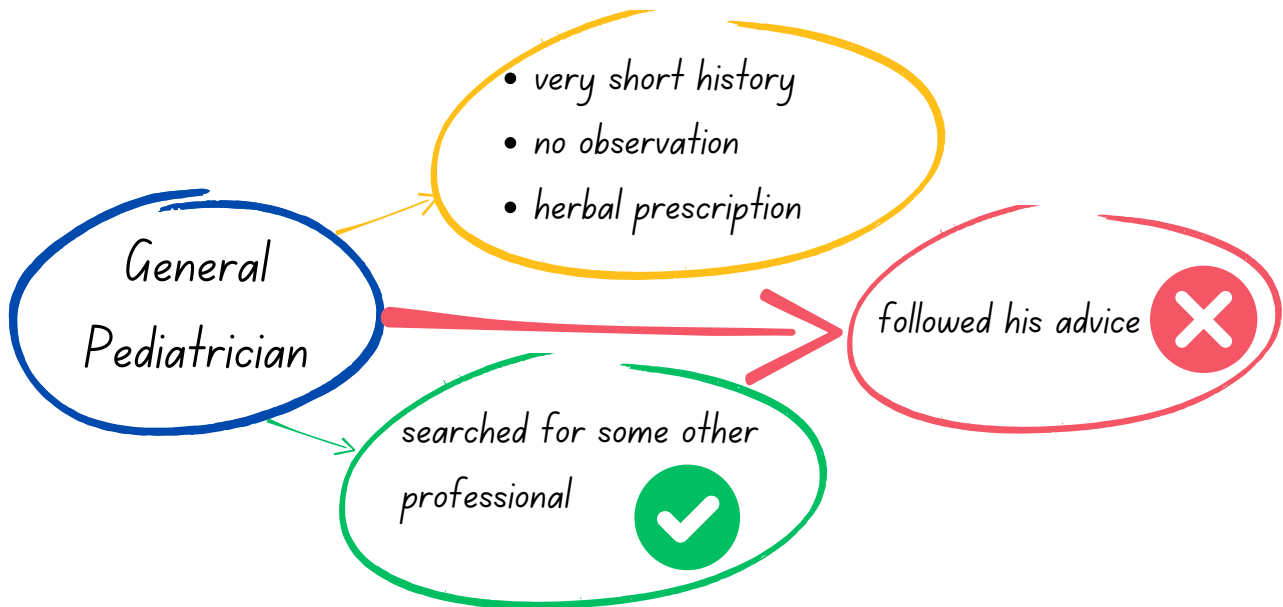
One of the first professionals that we consulted was a Psychiatrist who we knew from our medical college days. He extended his hand and said "اسلام عليكم /Asalamualaikum" to Musa. Musa shook his hand. This is a skill that we had spent a lot of time teaching Musa. So by witnessing just one skill, the Psychiatrist ruled out Autism.

What we did but shouldn't have done was that we trusted his opinion. We believed him and thought we were just overthinking and overanalyzing.

What we should have done instead was to search for some other professional, someone who understood Autism better. Because well, the presence or absence of a single trait certainly does not rule out a condition as diverse as Autism Spectrum Disorder.

Mistake # 2

Diagnosis/Evaluation



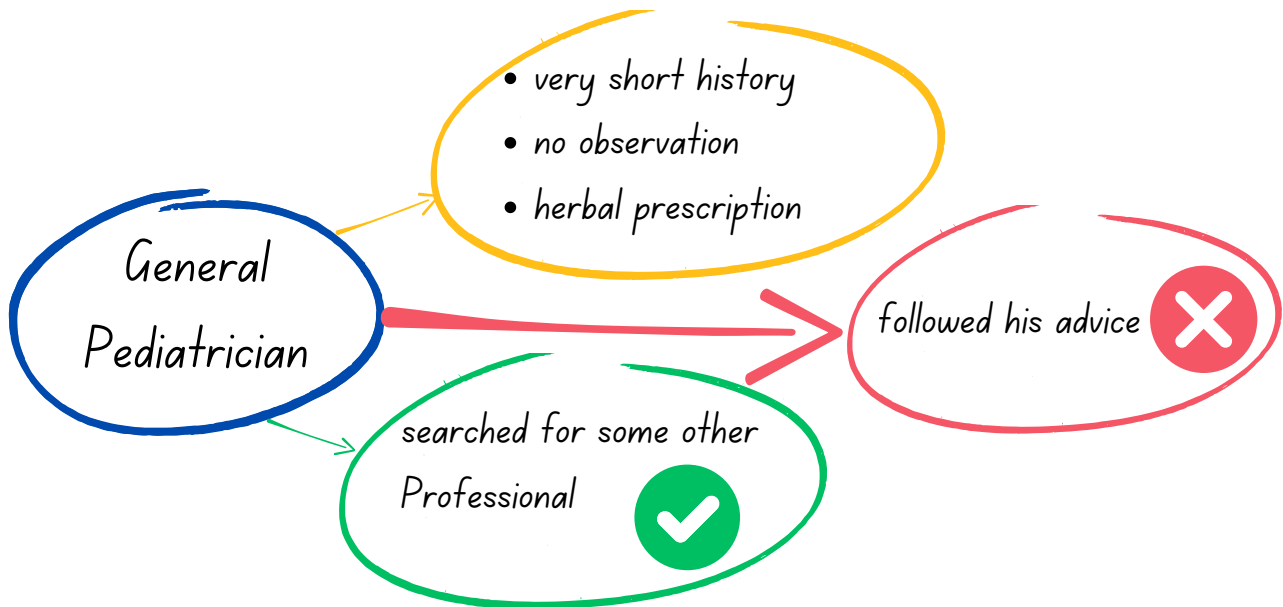
After a gap of a few months, Musa still wasn't speaking so we consulted a General Pediatrician.

He took an extremely short history. He immediately told me to take Musa back to the car because Musa was screaming and couldn't handle the loud overpacked consultation room. The Pediatrician gave Musa a prescription for a herbal drug, some sort of brain booster.

What I did was that I followed his advice. I was a doctor. I knew very well that there was no drug for Autism. Yet I forced my 3 years old to take a syrup that he clearly did not like. I would sit with him on my lap, one of my legs restraining him, my hand on his forehead, arm around his chest restraining his arms; while someone else would put a spoonful of the herbal medicine in his mouth.

Mistake # 2 (cont.)

Diagnosis/Evaluation



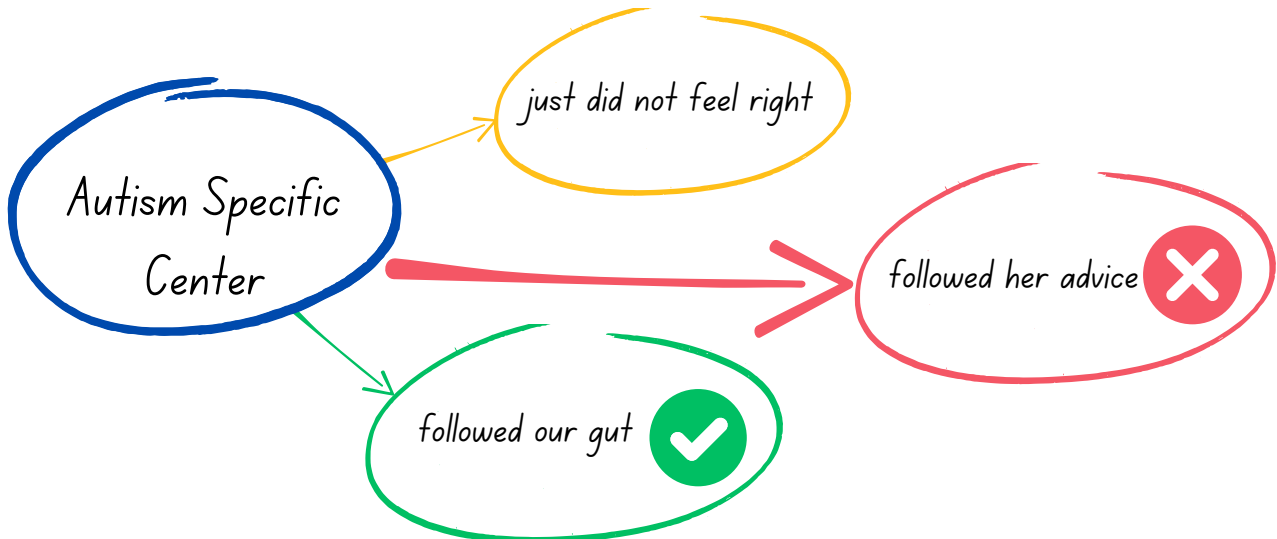
I was acting like a desperate parent and well, that is exactly how I felt those days.

I don't exactly remember how long I gave him that drug. Maybe a few weeks or a month. However, I shouldn't have done that.

What I needed, what Musa needed, was to get help from someone who truly was an expert in ASD.

Mistake # 3

Diagnosis/Evaluation

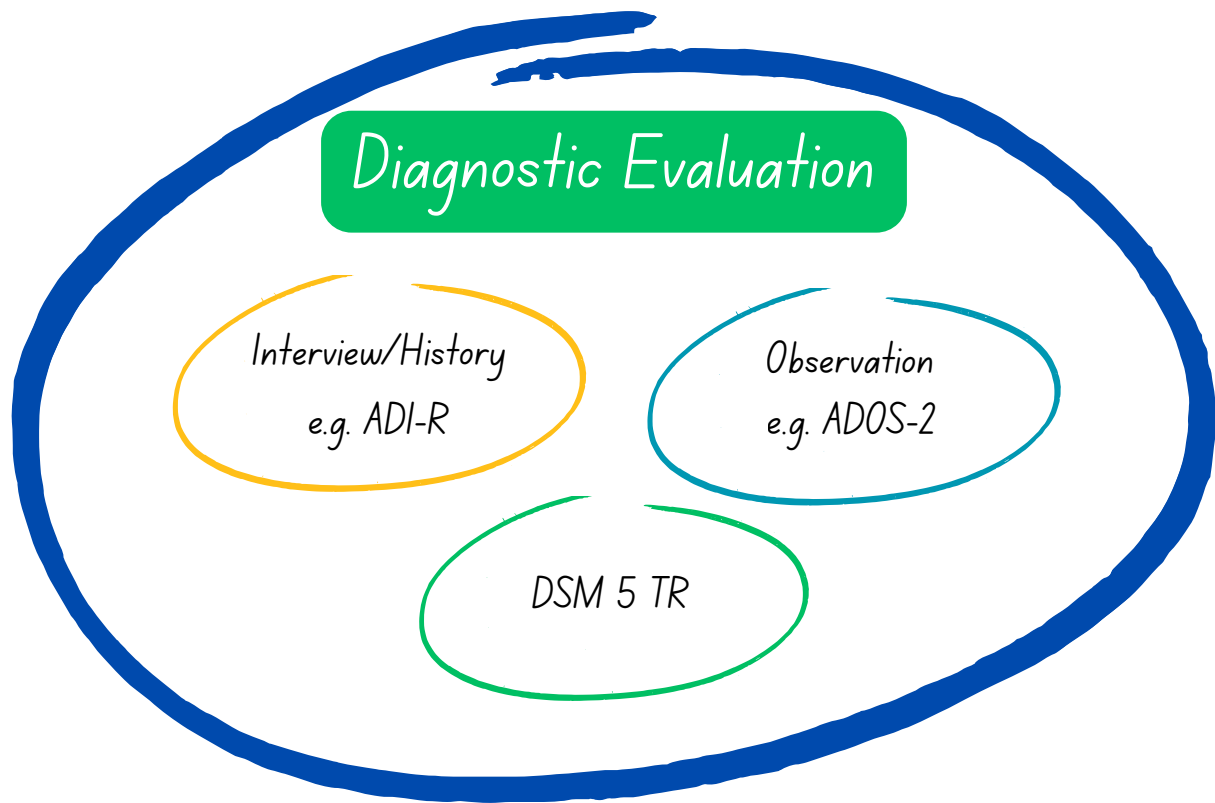


12 years back there weren't many Autism centers in Pakistan. There still aren't. So we had to travel to another city to get Musa evaluated at an Autism Specific Center.

The evaluation just didn't feel right. It was not very extensive. The Psychologist conducting it was dismissing any additional information that we were providing about Musa. She was only interested in the checklist she had in front of her. We asked her whether we should enroll Musa in a general education school and she said "Yes".

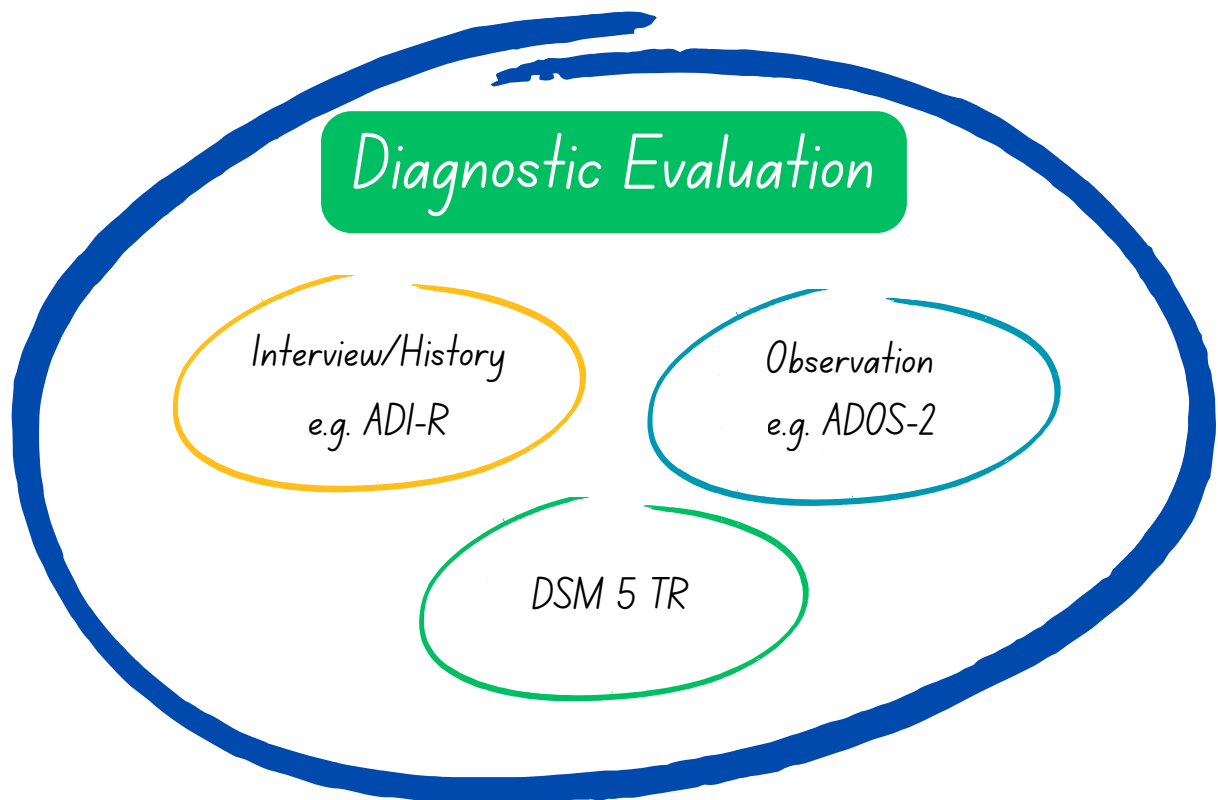
We received the report a couple of days after the evaluation and it said "no or mild signs of Autism". By that time I was convinced that Musa was Autistic so I clung on to the "mild signs" part. My husband who hadn't been living with us for the last 1.5 years due to his job placement latched on to the "no signs" part of the result.

Again , I should have followed my gut but instead we took her advice and enrolled Musa in a mainstream school.



So the question then arises what should a diagnostic evaluation for Autism look like?

Detailed interview and observation of the child are required to make a diagnosis of ASD. Information is gathered to see if the child fulfils the DSM 5 TR criteria for ASD. I won't be going into the details of DSM 5 TR right now.



I just wanted to briefly explain what ADI-R and ADOS-2 are. These are the most commonly cited gold standard tools for Autism diagnosis.

The ADI-R, the Autism Diagnostic Interview- Revised consists of 93 items and takes 1.5 to 2.5 hours to administer by interviewing a parent/caregiver.

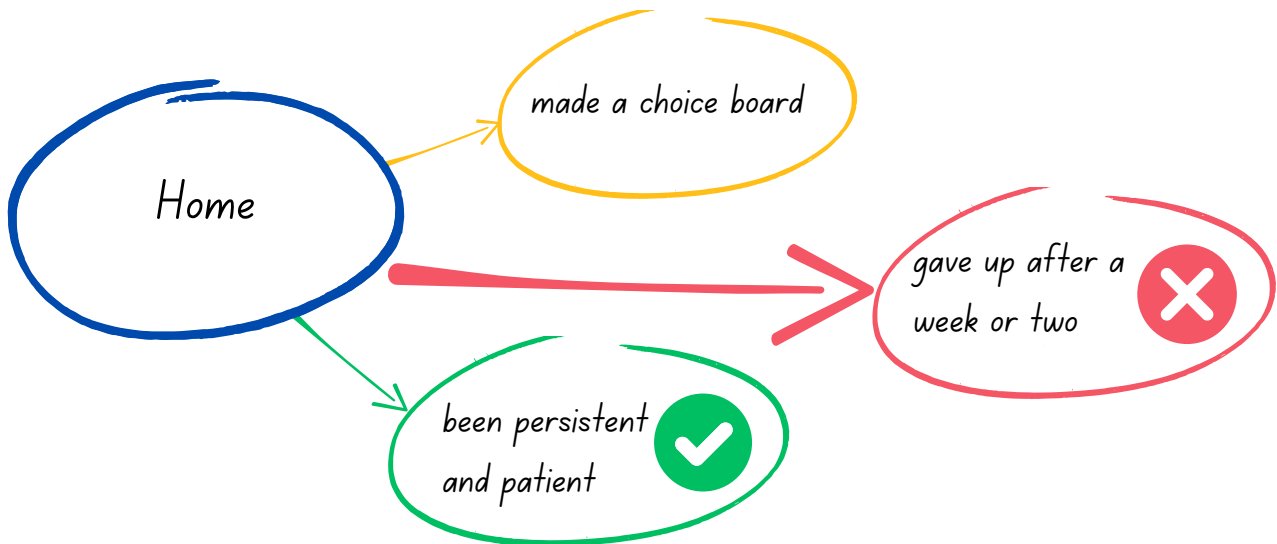
ADOS-2, the Autism Diagnostic Observation Schedule, second edition, is a semi-structured, standardized assessment for individuals suspected as having ASD. It takes around 1 hour to administer.

The point I just wanted to stress here is that the evaluation should be long, it should be extensive, lots of questions, lots of digging deep to truly understand the child's traits, plenty of opportunities to observe different traits.

So if someone rules out Autism based on a brief consultation, stay skeptical.

Mistake # 4

Visual Supports



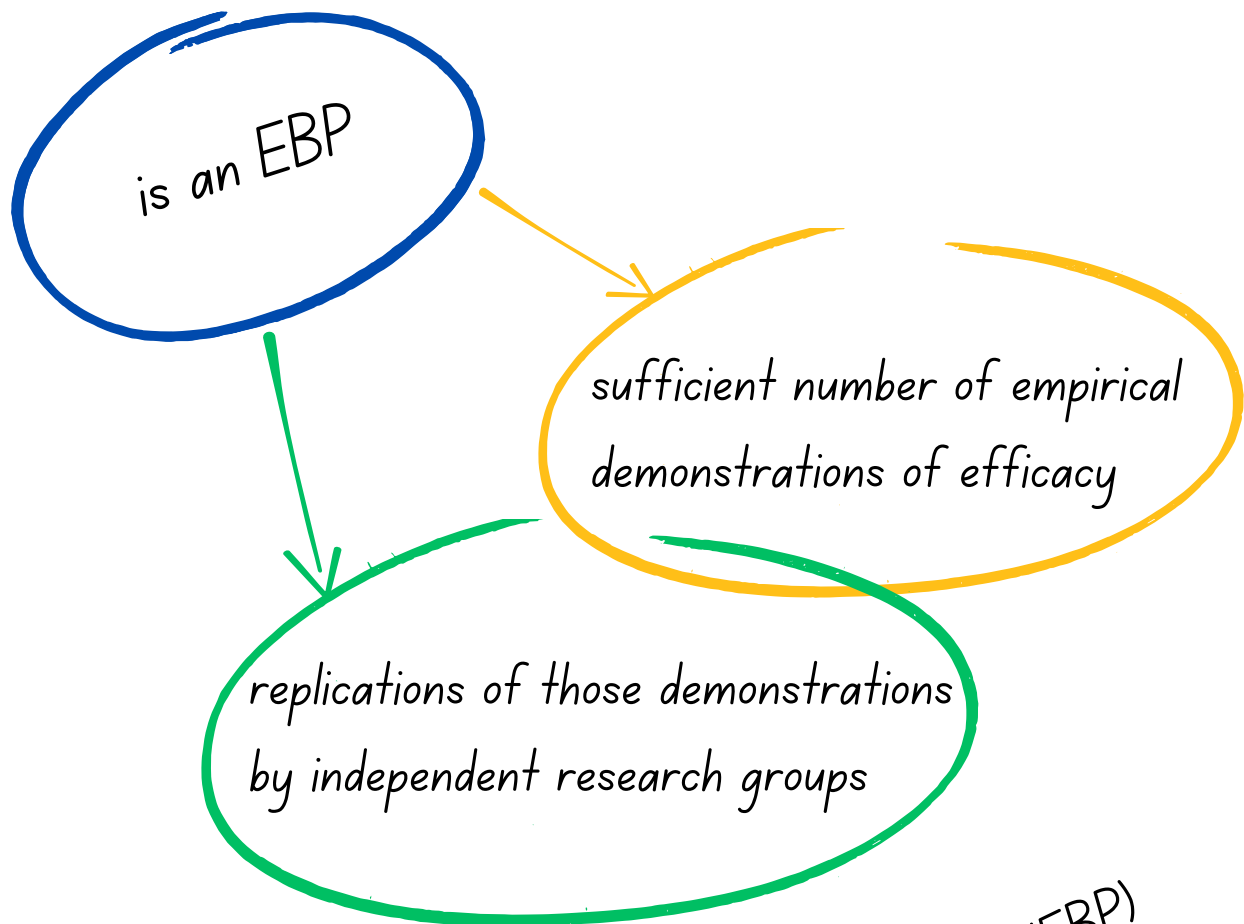
Now, coming to Mistake # 4. This is about my lack of trust in visual supports.

As a mother who thought her child had Autism and had absolutely no clue of how to support him, I searched the internet. I came upon the use of visual supports. I thus, made a choice board for Musa. This was around the time he was 3 years old. The visual support I made had pictures of food items that he liked.

I would try to get him to look at it and point to what he wanted. He paid no attention to it at all and I just gave up after a week or two.

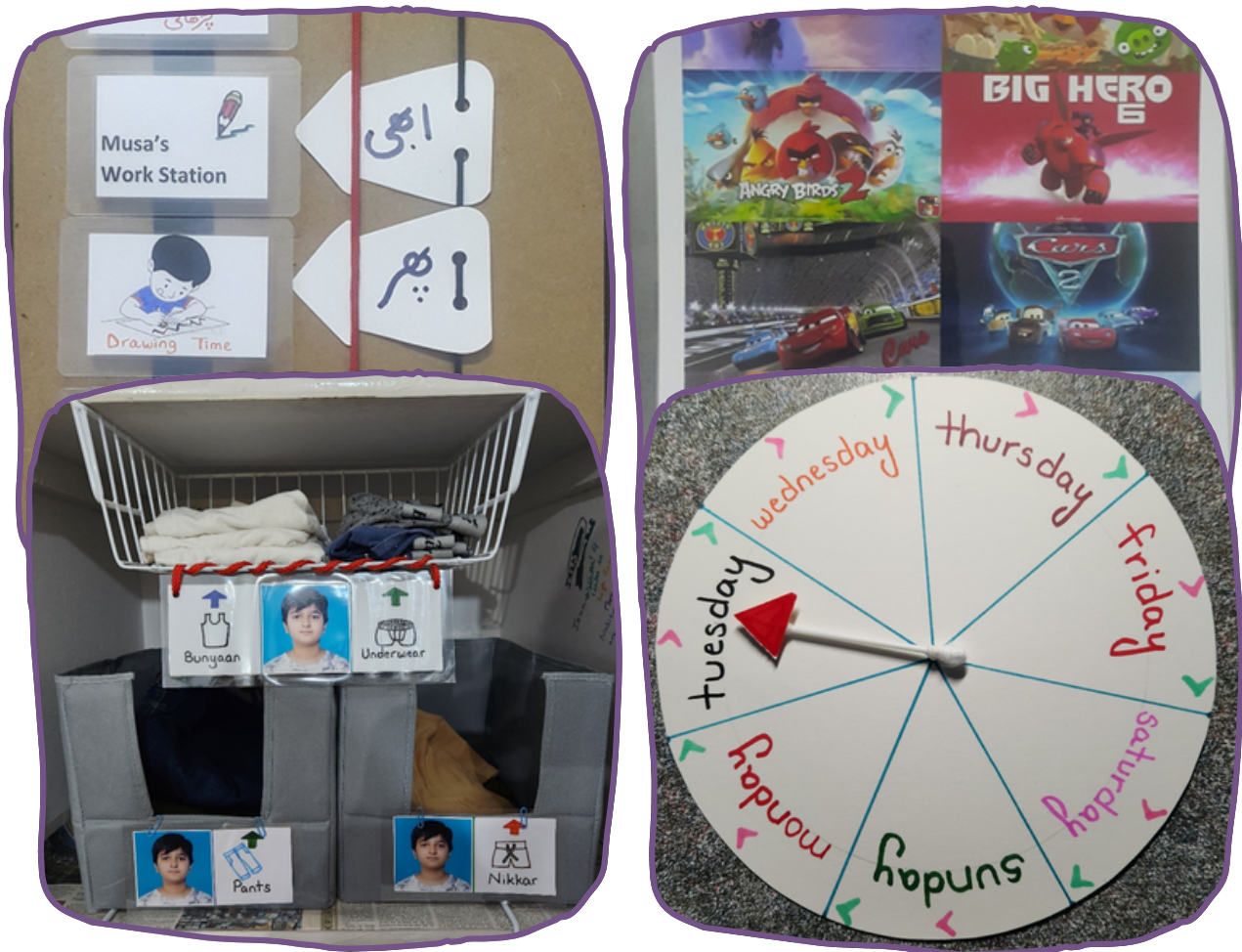
Visual supports take time but they do work. I wish I had been more persistent and patient.

Visual Supports



Use of Visual Supports is an Evidence Based Practice (EBP)
as per the NCAEP 2020 report.

Visual Supports

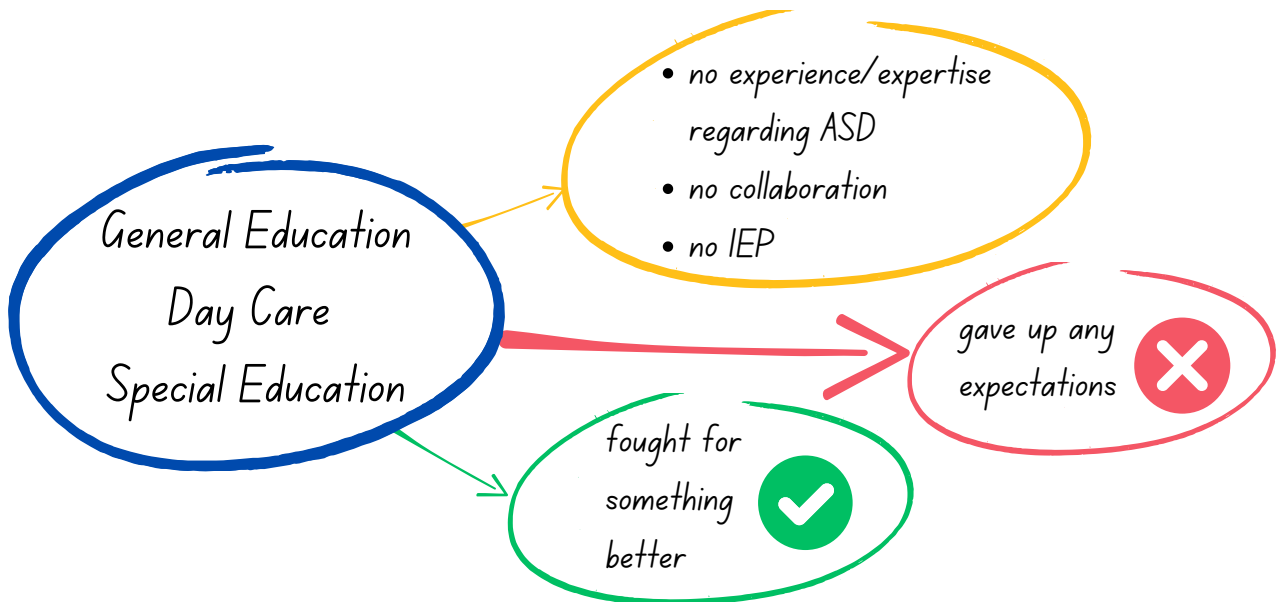


Visual supports can be anything from visual schedules or choice boards, labelling or a cue to help understand a concept etc.

These are pictures of some of the visual supports I made for Musa and have been a success.

Mistake # 5

Schooling



One of the most frequently asked questions I get is about Musa's schooling.

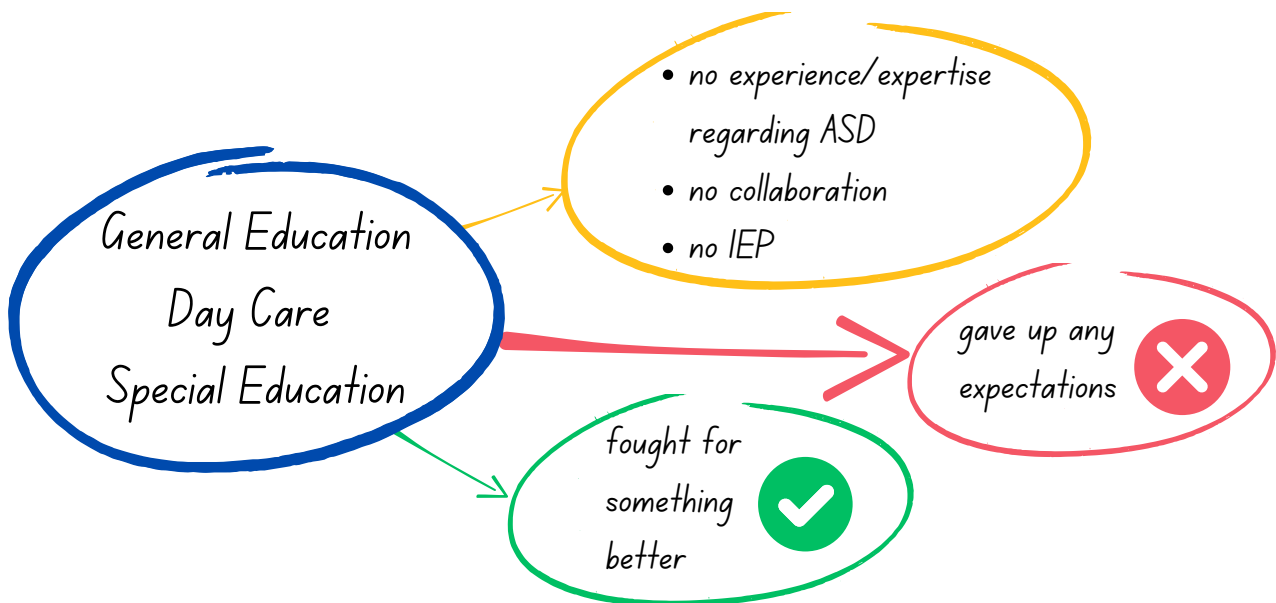
Currently, Musa is at home and I am trying my best to teach him. He does not receive any therapies from anyone else.

But in the past we have tried general education schools twice, he has been in a daycare setting and he also attended a special education school for a couple of months pre covid.

Chunking them all together, the staff had no experience or expertise regarding ASD in any of the settings and they were open about their lack of knowledge regarding ASD. There was no collaboration between us and the teachers and no one has ever made an IEP for Musa which is an Individualized Education Plan.

Mistake # 5 (cont.)

Schooling

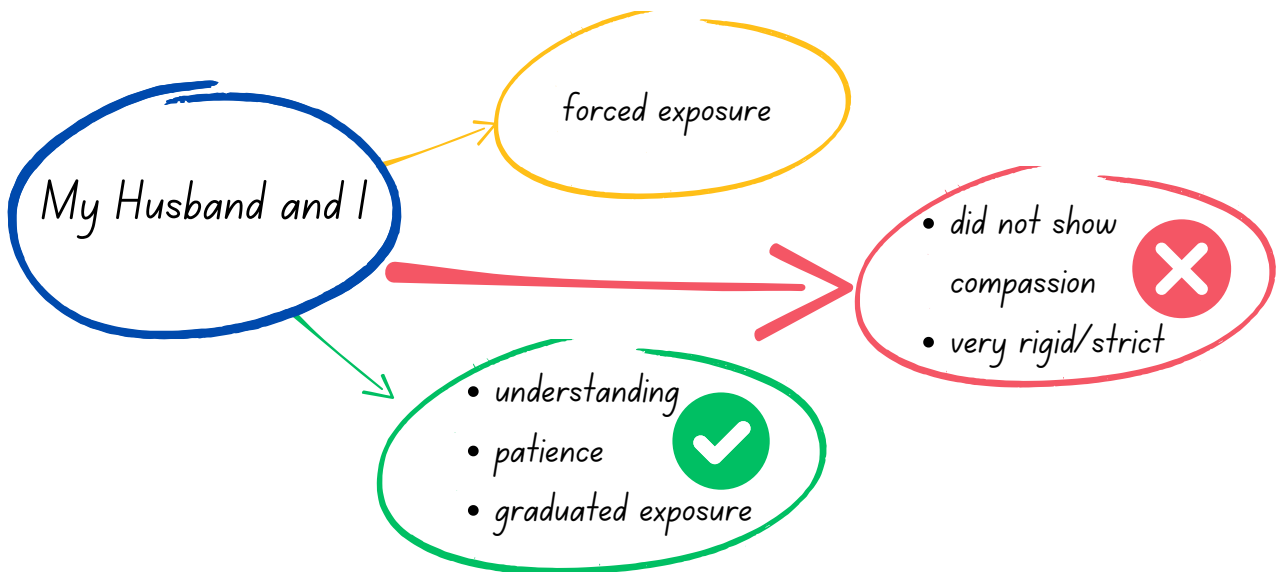


What we did was that we just gave up any expectations. We thought, well as long as he is in a safe environment while we are at work, it's okay. They have no clue as to how to support him neither do we. So well, what can we do. That was our thought process at that time.

What we should have done instead was: we should have educated ourselves, we should have fought for something better. We were paying for his education after all, we should have asked for some effort from the teachers, staff.

Mistake # 6

Sensory Differences



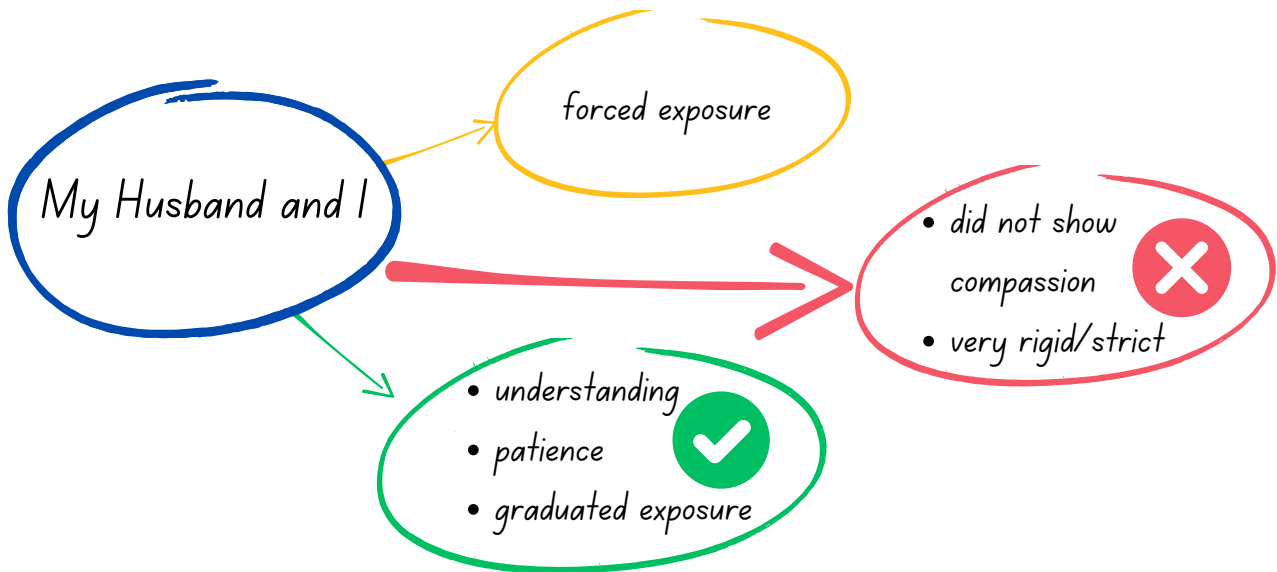
Mistake # 6 is about sensory differences.

Musa has had many sensory differences since the start. Hair cut was a challenge, trimming nails was not easy. He had a fear of loud sounds, many tactile hypersensitivities and yes, how can I forget, his super sense of smell.

So what we did when he was younger was forced exposure. We did not show compassion. We did not view him as having sensory challenges rather just viewed him as being difficult. We were strict, rigid and impatient.

Mistake # 6 (cont.)

Sensory Differences

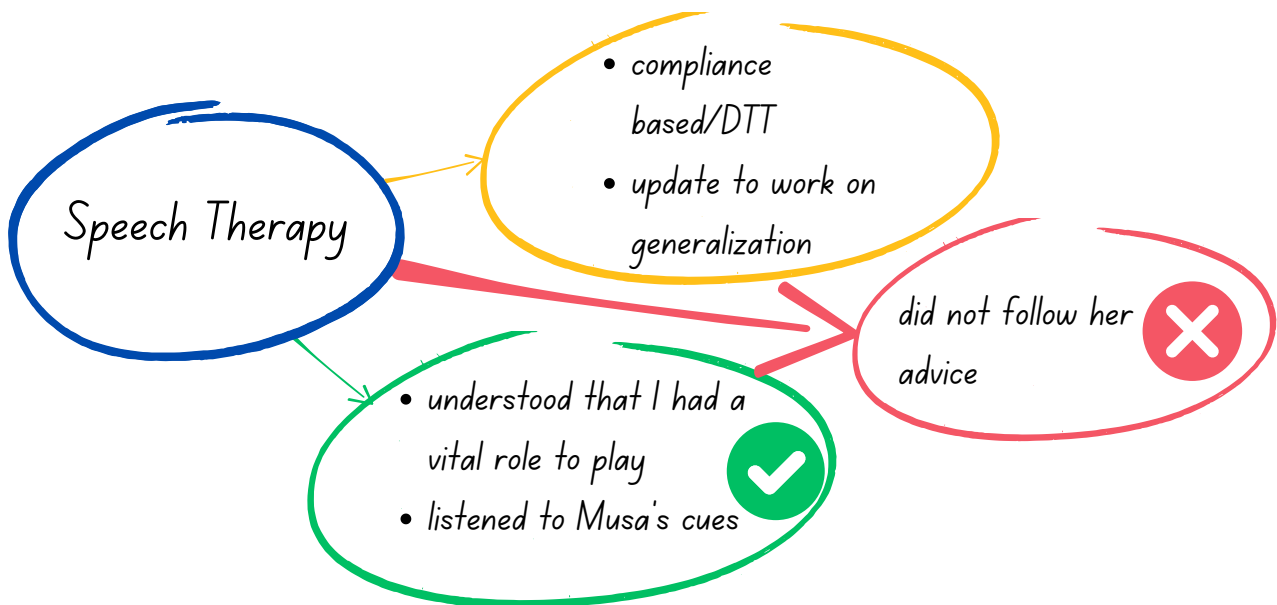


What we should have done then and what we do now is: We first try to understand why Musa finds a particular task difficult. Is some sensory difference making it hard for him? So understanding that Musa is genuinely experiencing something we aren't, helps us to be patient, helps us to show compassion.

So in situations that Musa finds difficult but can't be avoided like trying on new shoes, tasting new foods or shampooing; we remain calm, we take it slowly, we add visuals, gestures, we go the extra mile to make the experience as comfortable and predictable for him as possible.

Mistake # 7

Communication



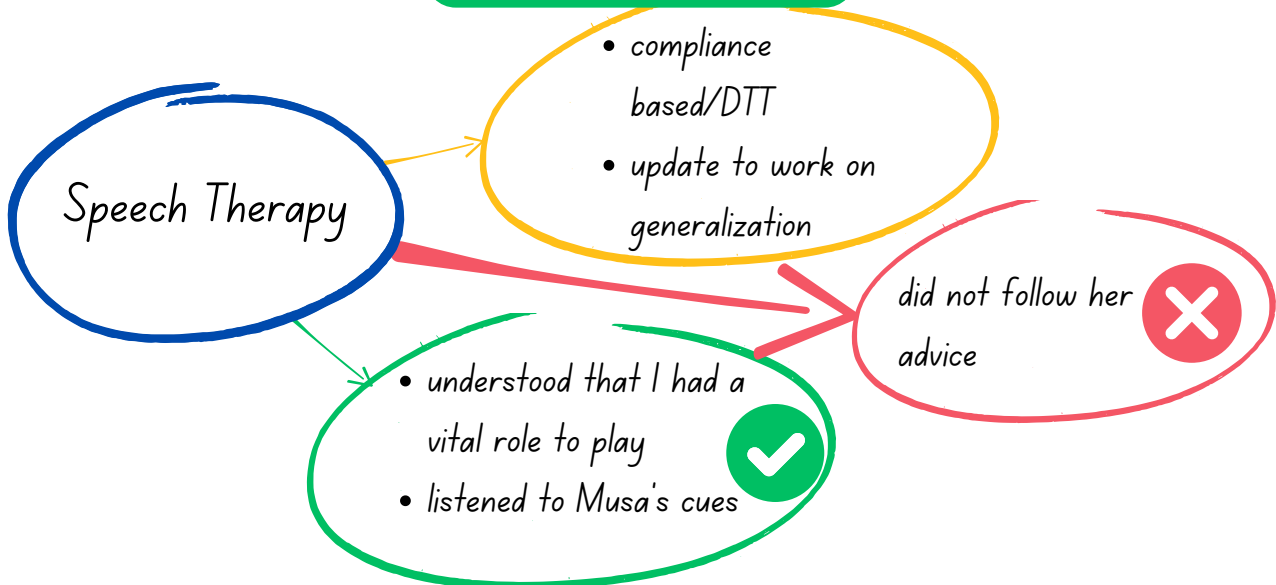
Like many other parents of Autistic kids, Musa's lack of communicative speech was what we stressed over the most when he was younger.

We dived straight into speech therapy.

It was a compliance-based, DTT type of speech therapy where Musa was receiving one on one reward based speech sessions using flash cards. Musa would attend these sessions three times a week for around 30 to 40 minutes each. We sat in the car while Musa had his sessions and the speech therapist would update us on the words she was teaching so that we could work on generalizing those words at home.

Mistake # 7 (cont.)

Communication



I did not follow her advice. I was extremely busy with my Pediatric training, night calls, weekend rounds. I was barely staying afloat.

I should have understood that I had a vital role to play. Autistic kids find generalizing skills difficult.

Musa was clearly not enjoying his speech therapy sessions. He would go in for them without resistance but we could see that he didn't want to. Whenever we were in the car driving in that direction Musa would sit up, tense up and look outside intensely. As soon as we crossed the junction and went straight instead of turning left Musa's whole body would relax. Going straight meant that we were going to his grandparents' house and not for speech therapy.

We should have paid heed to his body language, to his stern face, to his subtle cues. Instead we continued the speech therapy sessions for 4 years.

Mistake # 8

Communication



At home our whole focus was on his expressive language. We kept saying "Musa bolo" "Musa bolo" "Musa bolo" all day long.

We withheld reinforcers particularly food items from him and forced him to repeat the name of the item. We remained anxious, he remained anxious. It wasn't good at all.

What happened was Musa became quiet. No happy sounds, no humming. Just absolutely silent unless we prompted him to speak.

I wish we had modeled without expectation at that time. But we didn't know better. We were doing what we thought was right at that time.

Communication

DTT (Discrete Trial Training (DTT)):
is a one-to-one instructional approach (most typically) used to teach skills in a planned, controlled, and systematic manner. DTT is characterized by repeated, or massed, trials that have a definite beginning and end. (NCAEP 2020)



the Natural Language Acquisition Protocol to Support Gestalt Language Development



Okay, so I mentioned DTT. Discrete Trial Training is one of the evidence based practices mentioned by the NCAEP 2020 report.

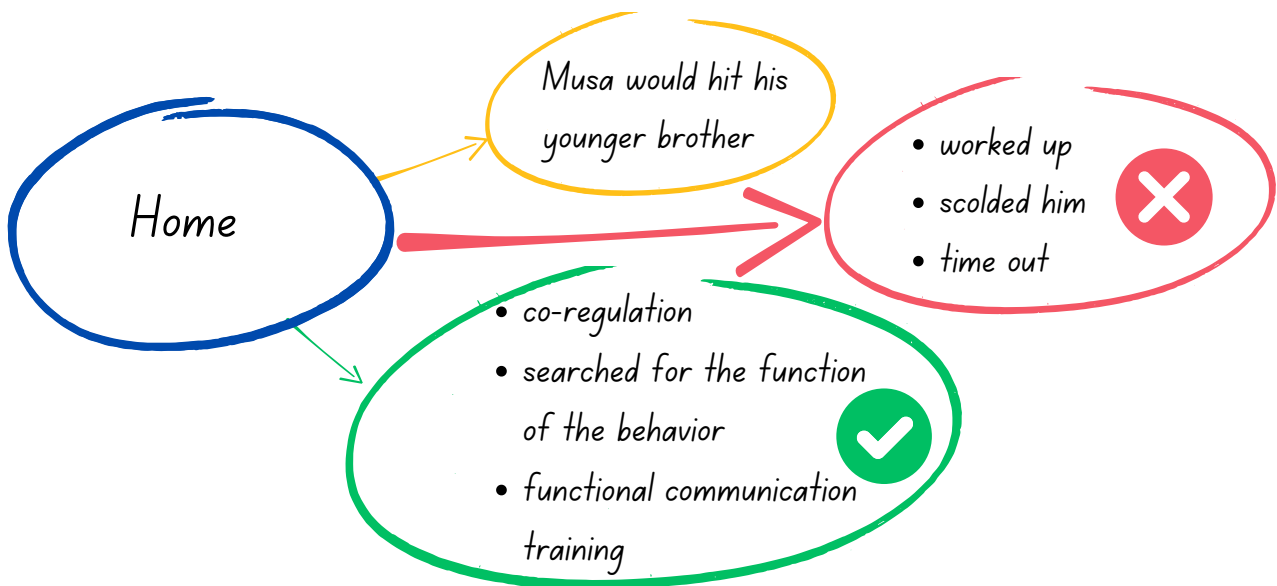
In my opinion, DTT works great while teaching academic or life skills but it doesn't help to improve spontaneous verbal communication. In Musa's case it did more harm than good.

For encouraging spontaneous communication the Natural Language Acquisition (NLA) Protocol to Support Gestalt Language Development is the way to go. NLA for GLPs (Gestalt Language Processors) is a whole world in its own. Check out the references at the end of this video to learn more.

But the key phrase to remember is "Model without Expectation".

Mistake # 9

Challenging Behavior/Dysregulation



Now coming to Mistake # 9 which is about what we as parents view as challenging behaviors but are rather more like panic attacks or dysregulated states.

At home Musa would frequently hit his younger brother Hashim.

We would get worked up. We would scold him and give him a time out, make him stand in a corner.

What we should have done instead was to remain calm, something which is called co-regulation. We should have searched for the function of the behavior and employed an EBP called Functional Communication Training.

Challenging Behavior/Dysregulation

Functional Communication Training (FCT):

is a set of practices that replace a challenging behavior that has a communication function with more appropriate and effective communication behaviors or skills. (NCAEP 2020)

For example

Musa got annoyed when Hashim talked too much.

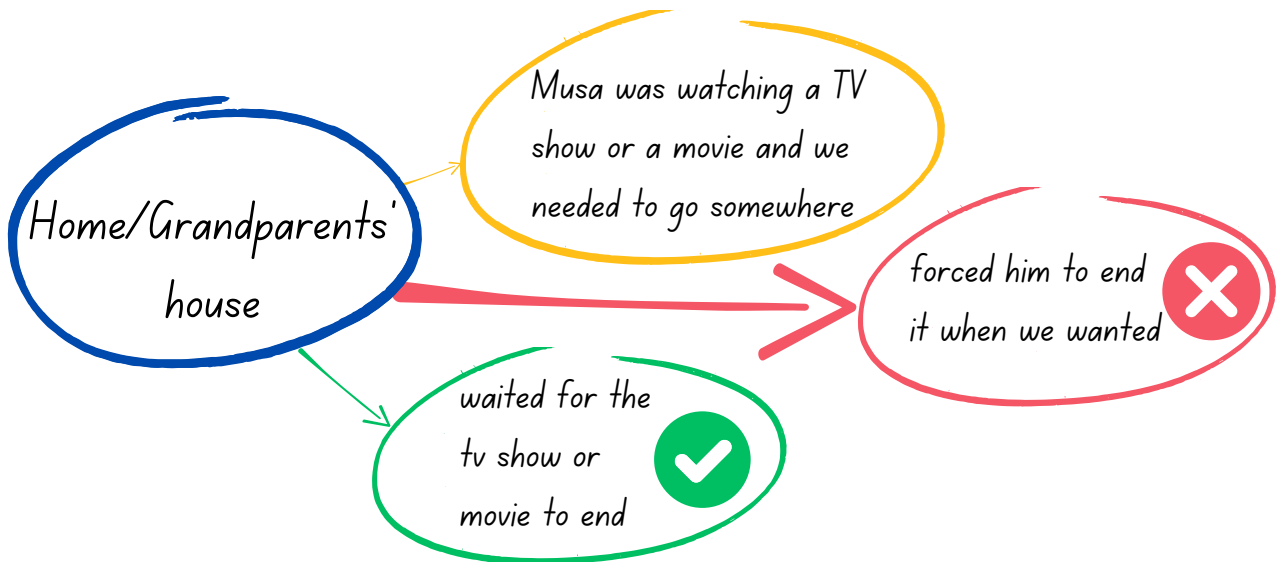
So we modeled "Hashim chup", "Hashim bus", "Hashim no" "Hashim jao".

Musa ماشاء الله picked up these phrases so quickly because they were meaningful for him. This is something the NLA framework also talks about.

Musa doesn't hit Hashim anymore. Well, he rarely hits Hashim anymore rather just tells him to go away or to be quiet.

Mistake # 10

Transitions



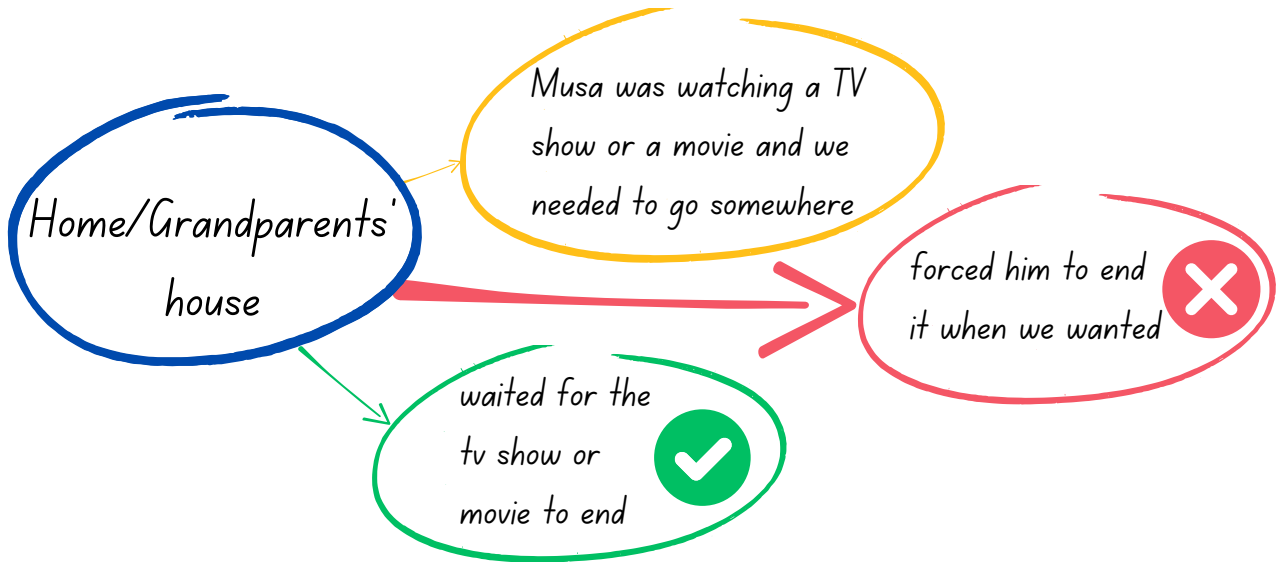
Mistake # 10 is about transitions.

At home or at Musa's grandparents' house when Musa was watching a TV show or a movie and we needed to go somewhere we would force Musa to end it, which caused a huge meltdown.

What we should have done was to wait for the TV show or movie to end.

Mistake # 10 (cont.)

Transitions

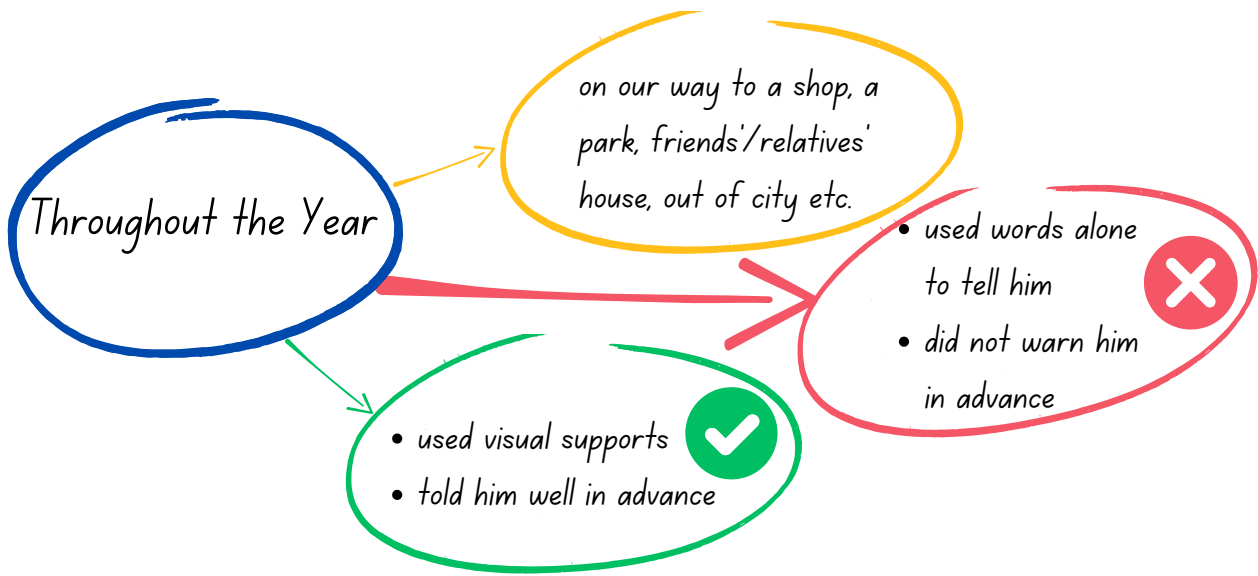


I came to learn about this by noticing that ever since Musa learned to play and forward movies that he watched via a USB drive on our TV, he wouldn't get upset when we told him that we needed to go out. He would turn off the television calmly but once back home he turned it on, forwarded the movie to the exact spot that he left it and would complete the movie.

So now if it's a TV show, we let it end; if it's something that can be resumed later we tell him that he can complete it once we come back. Back when he was having meltdowns he couldn't understand our verbal reassurance, now he can الحمد لله.

Mistake # 11

Changes in Routine



Changes in routine used to be very difficult all year round.

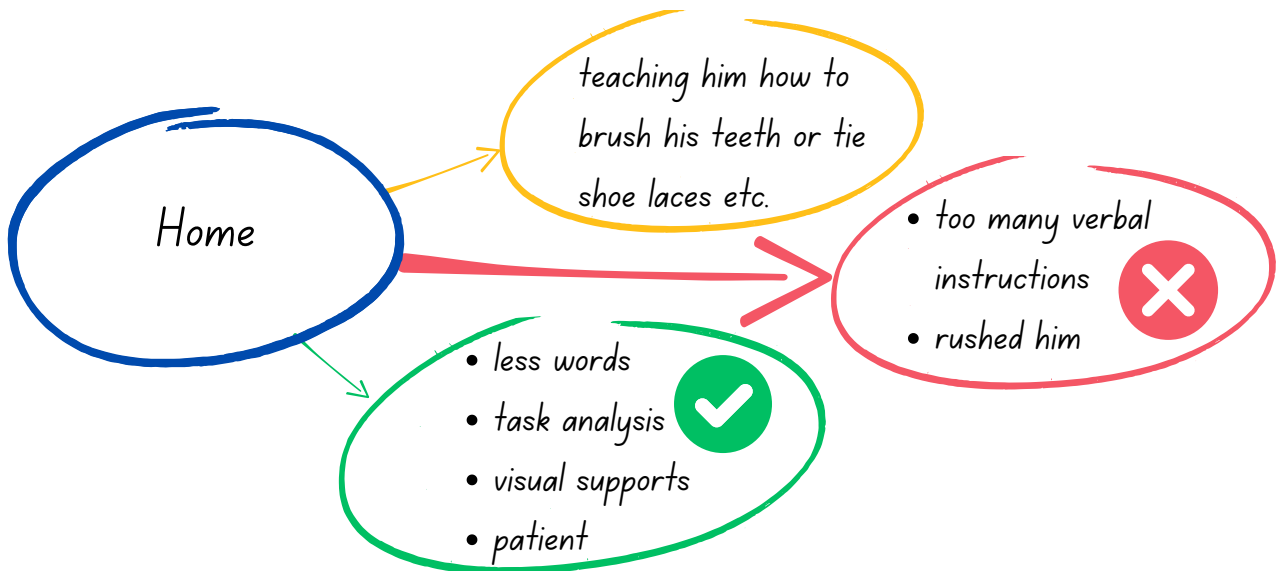
On our way to a shop, a park, friends' or relatives' house, out of city; we would only use words to explain to Musa where we were going. We did not warn him in advance. He certainly couldn't understand us no matter how much we spoke.

What we do now is use visual supports particularly a calendar and show it to him well in advance.

The unpredictability in the past used to cause him so much anxiety. So now we try to make sure that no big change is unexpected or sudden.

Life Skills

Mistake # 12



Last mistake that I'll be talking about today is about teaching Musa life skills.

While teaching him how to brush his teeth or tie shoe laces etc. I would use too many verbal instructions. I would rush him.

What I should have done was:

to use less words, to break down the skill that is employ an EBP called task analysis and use visuals.

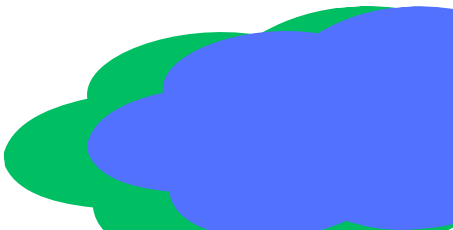
But most importantly I should have been more patient and الحمد لله I am now.



Life Skills


Task Analysis (TA):

is the process of breaking down a complex or "chained" behavioral skill into smaller components in order to teach a skill. (NCAEP 2020)





References

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