

# Noah's Hope

A Somali mother's experience with Autism: From diagnosis, to Somali community education.



## **Before autism was even a “thing”**

As new parents, we didn't know what autism was, or that we were supposed to be keeping an eye out for it—for that matter, when are parents ever told to “keep an eye out for it”? Noah went to scheduled check-ups, and appeared functional and happy. However, by 2 years, we had a growing list of suspicions:

- ❖ Lack of eye contact
- ❖ Repetitive gestures
- ❖ Delayed language skills
- ❖ Unaware of surroundings
- ❖ Fixation & preoccupation

## **Regular check-ups find Noah healthy**

Noah displays intense anxiety in healthcare facilities, resulting in inconsolable screaming and crying; furthermore, Noah's lack of cooperation makes routine assessments very difficult.

At Noah's 2 year check-up, we voice our concern regarding many of his observable behaviors; however, due to Noah's lack of compliance, and time constraints, the doctor is unable to establish if Noah may be within the autism spectrum. A hearing test is ordered.



## **I beg your pardon?**

We are in the examination room with the physician, awaiting Noah's hearing test. The doctor is simultaneously setting up her equipment and observing Noah. She then turned around to face me and said,

**“Your son has autism”**



## **What just happened?**

“I thought we were only testing Noah’s hearing today; you know, to determine if it was responsible for his general unresponsiveness?”

It’s only been 10 minutes;  
I have never met this physician before;  
the hearing test hasn’t even been administered yet; and the doctor is going to drop this on me without even a segue into the topic?

## All righty then...

Noah's hearing was fine. I was given literature on autism, which included guidance on how to proceed. I thought the process of diagnosing autism would take longer.

Weren't there supposed to be multiple visits to various specialists, or something? Is Noah officially diagnosed as autistic now? When calling agencies, do I start with "my son has been diagnosed with autism", or is not official yet? Does it need to be official?

*If it does need to be official, which officials make it official?*

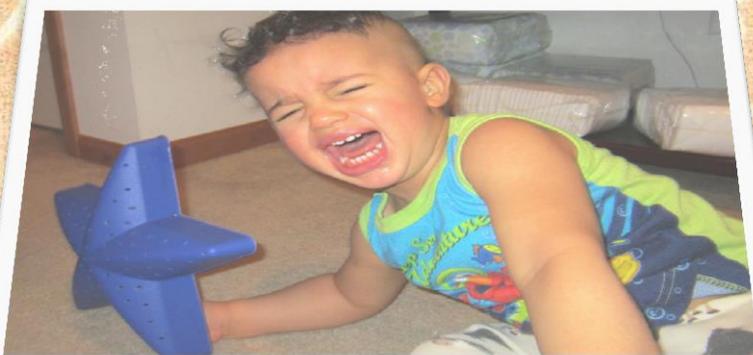


## **Saddle up!**

The whole family had to be brought up to speed in autism education; including our three teenagers & grandma. Books were ordered, videos were watched, online communities were joined.

### **New responsibilities**

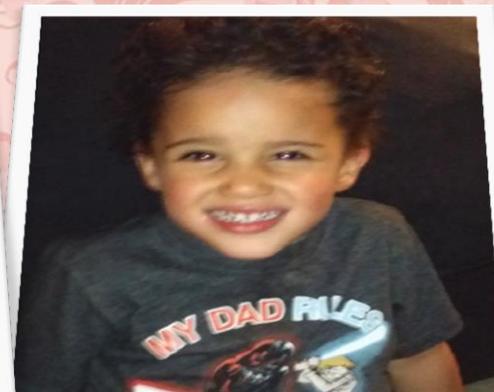
- \* Understand sensory needs
- \* Unique safety concerns
- \* Develop communications
- \* Dietary awareness
- \* Triggers of anxiety
- \* Physical therapies
- \* Occupational therapies
- \* Speech therapies



## The whole kit & caboodle

Noah receives ~50 hours a week of speech, occupational, and behavioral therapy; swimming is his favorite. In addition, we incorporate a dietary supplement regiment based upon noted deficiencies from biomedical lab reports. We are noticing steady improvements in Noah's situational awareness, fine motor skills, and speech capabilities.

There was a delay in Noah presenting the expected boundaries testing "terrible two's" behavior, however, shortly before his 3rd birthday, he laid claim to his behavioral birth-right with vigor, apparently making up for lost time.



# Autism & Somali Paradigms



## **Somali Perceptions & Approach**

In select cities, Somali language translators are available to the client; however, language is not the only barrier to effective communication. There is no translation for the word “autism”.

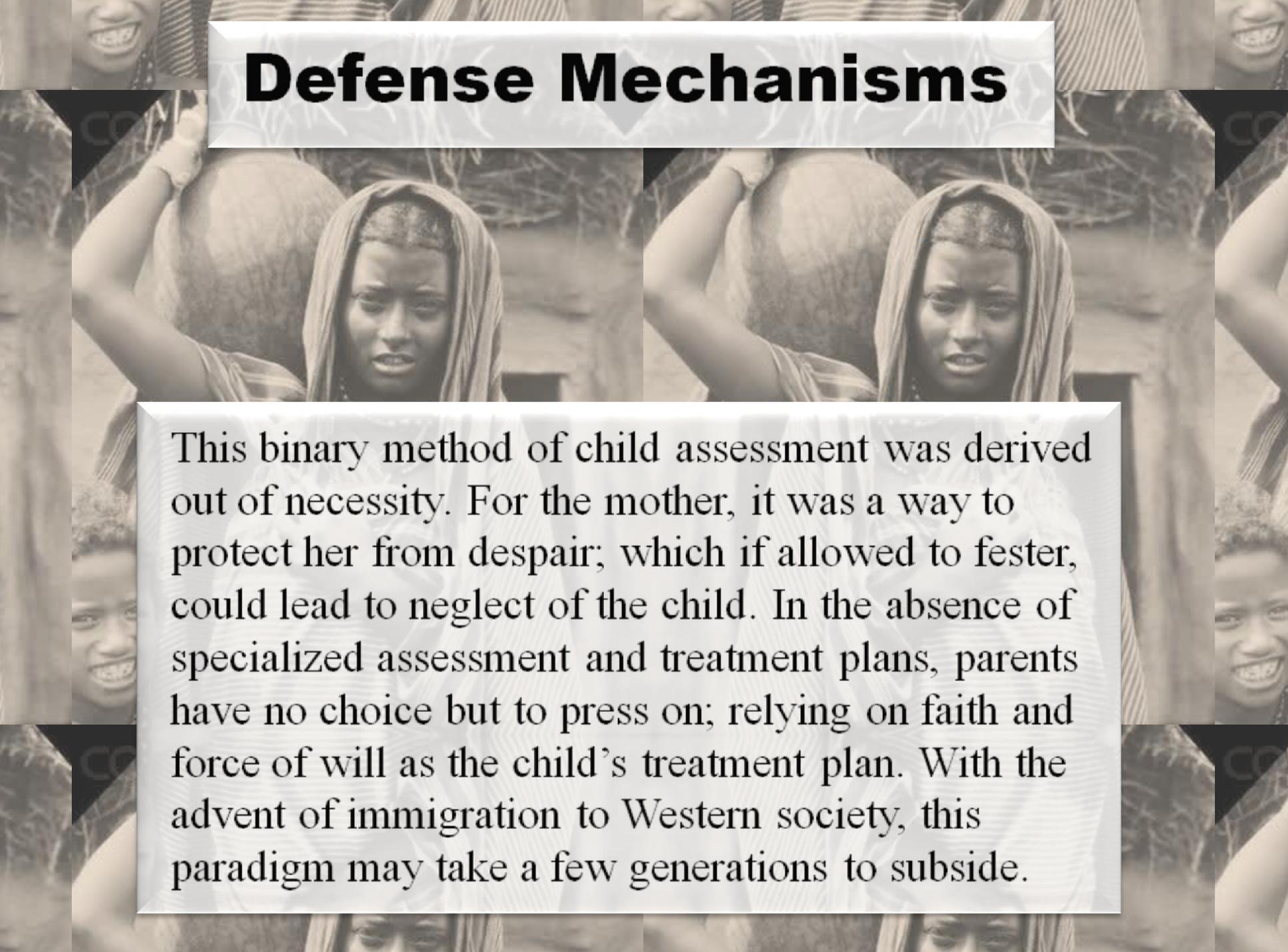
Furthermore, even if the translator’s skill level is top-notch, the concept of autism itself can be abstract. Professional Somali translators would be wise to prepare a script in advance for such cases instead of simply translating word for word what the healthcare provider is saying.

## All or Nothing

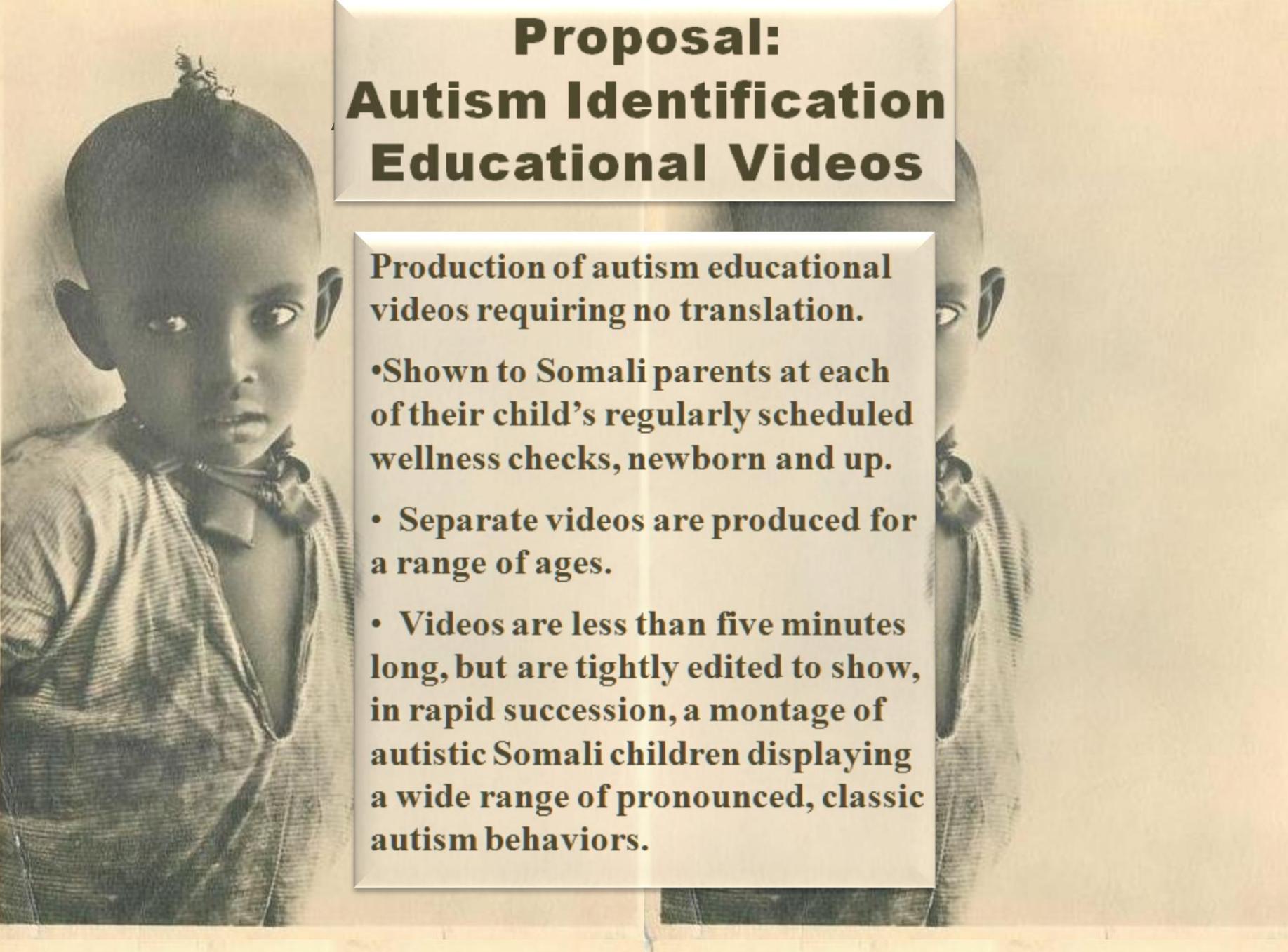
*“Cumugaagu wa fiican; yahay maaha doqon!”*  
*“Your child is fine; they are not disabled!”*

Traditional Somali culture is binary in assessing mental and neurological health; you are either fit-for-duty, or you are not. I was being kind in translating “doqon” as disabled, it is actually more akin to—the now defunct—“retarded”. If a mother’s instinct senses a subtle disability in her child, unless it is absolutely undeniable, family and friends will calm the mother with a supremely confident, “*yahay maaha doqon*” assessment.

# Defense Mechanisms

The background of the slide is a collage of images. The central image shows a woman from an African culture carrying a large, round, earthenware water pot on her head. She has a somber and distressed expression. This central image is surrounded by several smaller, semi-transparent images of the same woman, some showing her smiling and others showing her in a state of distress or pain. The overall tone is one of emotional suffering and resilience.

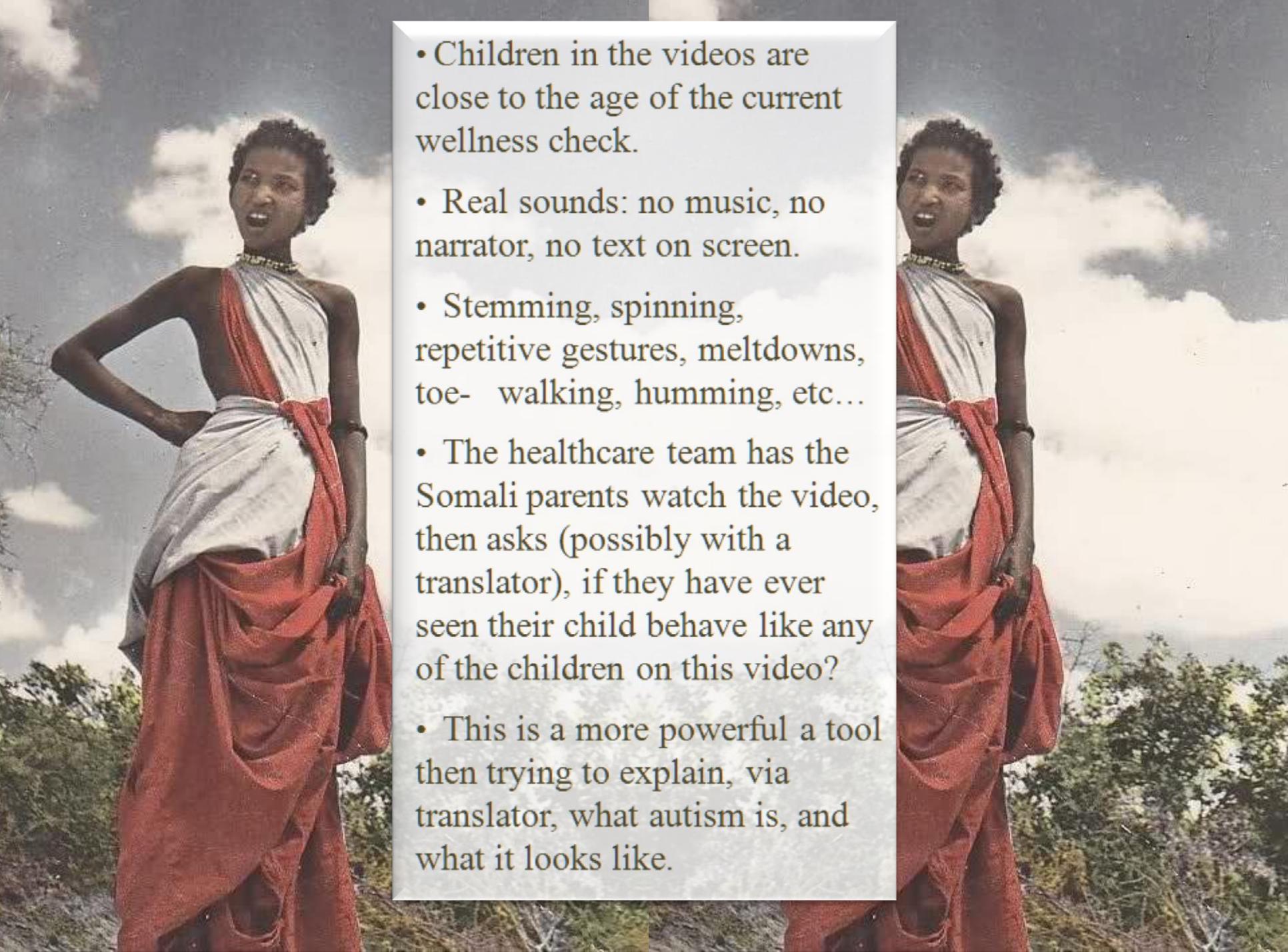
This binary method of child assessment was derived out of necessity. For the mother, it was a way to protect her from despair; which if allowed to fester, could lead to neglect of the child. In the absence of specialized assessment and treatment plans, parents have no choice but to press on; relying on faith and force of will as the child's treatment plan. With the advent of immigration to Western society, this paradigm may take a few generations to subside.



## **Proposal: Autism Identification Educational Videos**

**Production of autism educational videos requiring no translation.**

- Shown to Somali parents at each of their child's regularly scheduled wellness checks, newborn and up.**
- Separate videos are produced for a range of ages.**
- Videos are less than five minutes long, but are tightly edited to show, in rapid succession, a montage of autistic Somali children displaying a wide range of pronounced, classic autism behaviors.**



- Children in the videos are close to the age of the current wellness check.

- Real sounds: no music, no narrator, no text on screen.

- Stemming, spinning, repetitive gestures, meltdowns, toe-walking, humming, etc...

- The healthcare team has the Somali parents watch the video, then asks (possibly with a translator), if they have ever seen their child behave like any of the children on this video?

- This is a more powerful a tool then trying to explain, via translator, what autism is, and what it looks like.

Production requires the generous participation of Somali families interested in raising community autism awareness, and promoting early detection & intervention. A way to proceed, is to ask parents to make videos themselves, then donate it. The production quality will be low, but with professional editing could serve the purpose.



# Thank You

Power point  
by

Fatima MOLAS (mom)

&

James SharpLESS (dad)



Artwork

Vintage Somali photos Courtesy of  
mogadishuimages

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