

Parenting A
Child of Color
on the Autism
Spectrum:

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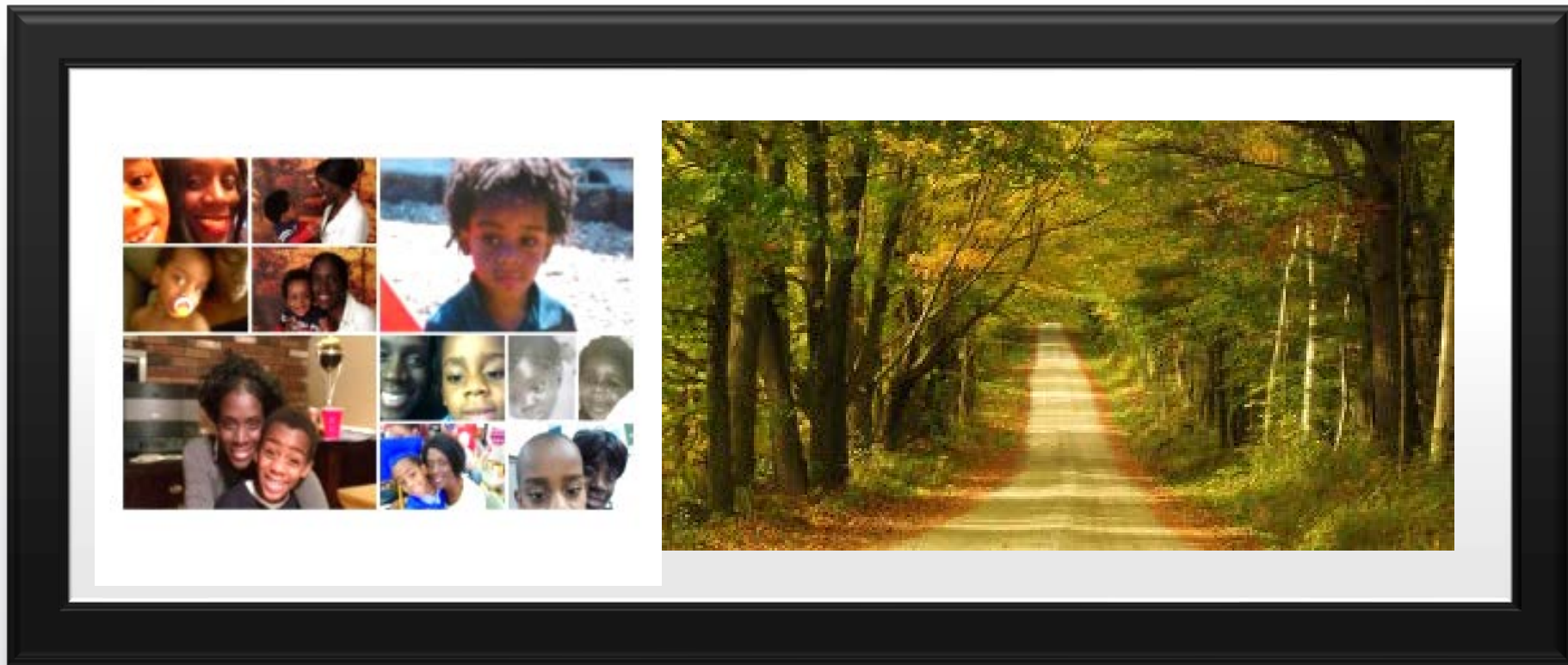
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The beginning: Joy, hope, promise



What lead me
to seek help
Initially

Problems with feeding

Difficulty swallowing

Gagging



The first referral

Getting the referral

Given a list of professionals to contact for services

No clear guidance on why he needed to be referred or what would happen after the referral

1st diagnosis: Developmental Delay

Understanding the diagnosis and services:

The Services:

Case Management

Occupational Therapy

Behavioral Therapy

Speech Therapy



From Developmental Delay to Autism



Bringing everyone up to speed



Having to rethink future goals



More challenges ahead



Accepting what is.....

Sharing the diagnosis with family members:

REACTIONS

NON- REACTIONS

SPOKEN AND

UNSPOKEN



Setting expectations:

For myself

My family

My friends

Professionals



Building Relationships:
Learning to Partner with Providers

Public school systems
Occupational Therapy
Behavioral Therapy
Speech Therapy



Transitions



New school.....



New Service providers.....




Telling story over again.....



Public School Years:





Strategies to starting new partnerships in the school system that have worked for me (*not in every school)

Meet	Meet with teachers and school personnel before school starts
Start	Start the meeting focusing on your child's strengths
Discuss	Discuss any potential concerns with behaviors
Provide	Provide information for what has worked in other environments
Create and open	Create and open dialogue about strategies that you use at home
Enlist	Enlist the help of your squad

The First School....

- The first unnamed school had no idea how to serve him and when I went to the open house and saw all of the clutter in the room, I knew it wouldn't work.....he stayed there one week.

The Second School

- Oh autism? Are you sure? Who diagnosed him.....
- He doesn't look like he has autism....
hmmnn...that looks more like ODD
- Oh but he is smart though.....
- Do you take him out in public
- We have a program that would be great for him.....it's called (a separate setting).....



Having to tell our story over again



New teachers and staff with different experiences



New behaviors due to transition



Past behaviors being restated

What are some challenges to building new relationships



The Third school....

Separated.....


No
mainstream.....

All children had
behaviors



Making the decision to transfer

- Joshua's behaviors had increased
- His sensory needs had become more pronounced
- Although his was progressing academically his social skills continued to lag
- I wanted him to be included in mainstream with supports



What are some challenges to building new relationships

Having to tell our story over again

New teachers and staff with different experiences


New behaviors due to transition

Past behaviors being restated

Fourth school

- He is too high functioning for AU and we can't manage him in mainstream....we don't know what to do with him.....maybe there is another program.....

Fifth school.....



WE HAVE A SMALL PROGRAM FOR KIDS
WITH AUTISM


HE WILL RECEIVE INSTRUCTION TO MEET
HIS NEEDS

THIS IS THE ONLY OPTION.....

IF YOU DON'T CHOOSE THIS OPTION, WE
CAN'T PROVIDE ADDITIONAL SUPPORTS IN
MAINSTREAM.....

.....

Fifth school.....



REALIZING THAT THE INFORMATION
WAS NOT ACCURATE

CHALLENGING A BROKEN BELIEF
SYSTEM

THE PROS AND CONS OF LITIGATION

WHAT I HAVE LEARNED THROUGH
THAT PROCESS



Learning to trust the educational system again

- Working with others to find the best fit
- Being a part of the IEP meeting where the “I” actually means individualized
- Having open and honest communications about what is needed
- Truly having a reciprocal partnership with the school that benefits Joshua and myself



Sixth School

- We understand that this has been a discouraging journey
- We want your son here
- We will work with you and him
- We will love on him
- We are so happy to have him here
- He is such a wonderful kid



Other challenges within the school system

- When there is no “I” in IEP

- when parents feel disempowered

-when the IEP meeting turns into a “everything that your child has done wrong session”

Strategies for surviving the IEP meeting that has worked for me

Get a good night sleep

Bring a friend to support you and take notes

Read the IEP highlight anything that is unclear

Stay calm and focused

Ask questions

If the meeting becomes too intense end the meeting and request another meeting

Do not sign anything that you do not agree with



Request a new IEP meeting



Enlist your squad to assist with questions



Invite a friend to accompany you to meeting



Make any additional requests in writing



Ask for a copy of any “evidenced based” practices they are using



Continue to allow open communication and document all conversations and efforts



Always search for a win/win and a resolution to conflict

IEP meeting continued



//////
“ AU Squad (The importance of building strong support system)

- Auntie
- BFF
- My brother
- Ms. Wendy
- Joshua’s Pediatrician
- Joshua’s tutor
- ALL OF MY FRIENDS ABSOLUTELY LOVE AND SUPPORT JOSHUA

How I went from anger to advocacy

Learned my child's educational needs and his rights

Understand the legal aspects of the IEP and its purpose

Began to offer the school systems resources to help them help my child

Stayed focused on the issue at hand and did not feed into any negativity

Documented all meetings and followed up with email

Any "policy" statements made I requested a copy of the policy

Continued to stay involved and ask questions even when I was discouraged with the school system

NOTE TO SELF
and Others

REMEMBER TO BREATHE

I AM ADVOCATING FOR MY SON

I AM ADVOCATING FOR ALL CHILDREN
WITH SPECIAL NEEDS

I AM A CHANGE AGENT

I AM NOT ALONE

IT'S A MARATHON AND NOT A SPRINT

Special Thanks



First and foremost I would like to thank my son Joshua without him none of this would have been possible.....



I would like to thank everyone of my family and friends who have supported and continues to support both Joshua and me throughout our journey



I would also like to thank my mentor Sherry Mergner, MSW, LCSW and CIDD for giving me opportunity to share our story and bring awareness.

Questions from
participants....

