C.H.A.R.G.E. SYNDROME

The Puzzle, The Practical & Possibilities

My table setting

Married 30 years

3 young adult children

Mom of a CHARGER

Family Specialist

DEI Consultant

H&V HQ Board President

Family Faculty LEND UNC

PHE!

Definition /Diagnosis

The Puzzle

C.H.A.R.G.E SYNDROME

<https://www.chargesyndrome.org/>

Co-occurring conditions

The Uniqueness of C.H.A.R.G.E. Syndrome

When you’ve seen one kid with CHARGE Syndrome, you’ve seen one kid out of thousands with CHARGE

The Practical:

How it weaves together

Growing up with CHARGE Syndrome

Child

Family

Partners

Siblings

Individuals

Health System

Education

Family & Culture

Family Affair

Malik’s story

ALL ABOUT ME

* My Medical Diagnosis: **C.H.AR.G.E. SYNDROME** [**www.chargesyndrome.org**](http://www.chargesyndrome.org/)
	+ **C** Coloboma (eyes)-retinal detachment
		- Functional vision in Right Eye.
		- Light perception left eye
		- Legally blind
	+ **H**  Heart –**Central** ***Arterial Ventricle Canal Repair 4/96***
		- current Mitral Valve regurgitation
	+ **A** Choanal Atresia(blockage of nasal membrane or bone)-none
	+ **R** \_ Retardation-cognitive and developmental
		- (cognitive level: @3-6, plus)
	+ **G** Genital abnormalities- undescended testes ***repair 3/99***
	+ **E** Ear Abnormalities – ***profound deafness***-95^ db
* \*\* **COGNITIVE DELAYS: NON –VERBAL(ASL/gestures)**
	+ Other: TEF (tracheoesophageal fistula) ***repair 3/5/96***
	+ GERD, Asthma, Migraines, Seasonal Allergies, Tics

The Possibilities

Living their BEST Lives

PERSON CENTERED PLAN

* Began school at ENCSD in spring 2005
* No hospitalizations since 2011
* Eating a variety of foods
* Potty trained
* Completes chores
* Improved balance and mobility
* Increased independence
* Grown to 96 lbs.
* Increased use of ASL
* Occasional outbursts
* NOW!

FEARS

“My biggest fear as a parent is preparing for a time that I thought Malik would never have..

The Future

* Unable to live independently
* Becoming a burden to siblings
* Not living in a safe environment
* Experience pain, molestation, or abuse
* Loss of vision or health
* Death
* Medication overdose
* Outbursts getting worse
* Public safety
* Choking
* Dental health decline
* Psychiatric concerns
* Esophageal damage
* Social isolation

DREAMS

* Live independently
* Productive member of society
* Happy & healthy
* Safe everywhere
* Work
* Community of people who love & support him
* Communicate
* Read
* Have friendships
* Able to go on family vacations

ACTION PLAN

|  |  |  |
| --- | --- | --- |
| Task | Person Responsible | Timeline |
| Increase expressive & receptive communication 1. Complete communication matrix
2. E & R symbol dictionaries

iPhone- I can connect | School staff, familySchool staffCarol, Mom | ASAPJuly 1st, 2016/assessment |
| Deaf- Blind training for staff* + Contact Helen Keller
	+ ECU TSP
	+ Contact Mike F. & Marilyn T.
	+ Contact ENCSD to arrange training
	+ Funding for Mike & Marilyn: transition training
 | Mom, Andrea/ JulieMom MomMom | ASAPOngoing  |
| DSB contact/ DEE Tripp/ Duke Eye | Mom | July 5, 2016 |
| Increase CAP workers and agency support * + Day program
	+ Create webpage/ passport
 | School job coach, MomDad | In progress |
| Create experience books | Staff | September, 2016 |
| Create behavior goal- motivators & consequences | Staff | After July, 2016 |

Jacob

Creative Outlets

Productivity

Manipulatives=purpose

# “We all have that possibility, that potential, and that promise of seeing beyond the seeming.”- Maya Angelou

Reflections and Questions

Resources

<https://www.chargesyndrome.org/>

TSBVI

Texas Chargers Inc.

Local Deafblind Projects

[www.ncdb.org](http://www.ncdb.org)

HKNC

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