

**CULTIVATING ACCEPTANCE IN  
FAMILIES LIVING WITH AUTISM  
SPECTRUM DISORDER**

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- SOME USEFUL DEFINITIONS OF THE VERB TO ACCEPT:**
- TO RECEIVE WILLINGLY
  - TO BE ABLE OR DESIGNED TO TAKE OR HOLD
  - TO GIVE ADMITTANCE OR APPROVAL TO
  - TO ENDURE WITHOUT PROTEST OR REACTION
  - TO REGARD AS PROPER, NORMAL, OR INEVITABLE
  - TO RECOGNIZE AS TRUE

- ACCEPTANCE IS NOT:**
- STAGNATION
  - DESPAIR
  - RESIGNATION
  - GIVING UP
  - COMPLACENCY
  - SILENT RESENTMENT
  - OPTIMISM

- TIP: OPTIMISM VS. HOPE**
- OPTIMISM IS, ULTIMATELY, A FORM OF DENIAL WHILE IT IS A PLEASANT, SEEMINGLY HARMLESS STATE OF MIND THAT PSYCHOLOGISTS TYPICALLY ENCOURAGE, IT IS ULTIMATELY THE BELIEF THAT "SOMETHING WILL GET BETTER," DESPITE A LACK OF EVIDENCE, OR EVIDENCE TO THE CONTRARY
  - HOPE, ON THE OTHER HAND, IS SIMPLY THE BELIEF THAT ONE'S ACTIONS MATTER: THAT MY CHOICES HAVE SOME IMPACT ON THE WORLD. THE RESULT CAN INDEED BE SOMETHING "BETTER" THAN IT WAS, OR IT MAY SIMPLY BE SLIGHTLY BETTER THAN IT WOULD HAVE BEEN IF I HAD MADE A DIFFERENT CHOICE. HOPE IS COMPATIBLE WITH ACCEPTANCE.



- ACCEPTANCE IS A PROCESS, NOT A PLACE**
- WE DO NOT ACCEPT SOMETHING LIKE AN AUTISM DIAGNOSIS AND THEN MOVE ON
  - AS OUR CHILD GROWS AND THE WORLD CHANGES, SO MUST OUR APPROACH TO ACCEPTANCE
  - WE WILL FIND ACCEPTANCE EASIER ON SOME DAYS THAN OTHERS
  - A COMPONENT OF ACCEPTANCE IS ACCEPTANCE THAT WE WILL SOMETIMES STRUGGLE WITH ACCEPTANCE, AND SOMETIMES FAIL
  - IT IS POSSIBLE TO ACCEPT MY CHILD'S CONDITION AND FIGHT FOR MY CHILD AT THE SAME TIME

## AUTISM IS UNIQUE

- WHILE IT MAY SHARE CERTAIN ELEMENTS WITH MOOD DISORDERS LIKE DEPRESSION OR ANXIETY, DEVELOPMENTAL DISABILITIES LIKE INTELLECTUAL DISABILITY, AND PERSONALITY DISORDERS, AUTISM SPECTRUM DISORDER (ASD) HAS UNIQUE CHARACTERISTICS THAT DEMAND WE VIEW IT IN ITS OWN LIGHT, ITS OWN CATEGORY.
- EACH PERSON WITH THE DIAGNOSIS OF ASD HAS A UNIQUE AND SPECIFIC SET OF SYMPTOMS (AND DEGREE OF SYMPTOMS) THAT ALSO CHANGE OVER TIME, PARTICULARLY DURING CHILDHOOD AND ADOLESCENCE



Always  
Unique  
Totally  
Interesting  
Sometimes  
Mysterious

## THE LABEL: PROS AND CONS

- SOME PARENTS, AND INDIVIDUALS WITH THE DIAGNOSIS, EMBRACE THE DIAGNOSIS, AND FIND IT A GREAT COMFORT, ESPECIALLY AFTER MANY MISDIAGNOSES AND UNHELPFUL (OR EVEN HARMFUL) INTERVENTIONS
- OTHERS RESENT BEING CATEGORIZED. AFTER ALL, EACH OF US IS A UNIQUE INDIVIDUAL. WHY DOES ONE PERSON'S SET OF HABITS GET LABELED A DISORDER, WHILE SOMEONE ELSE'S IS CONSIDERED "TYPICAL?"
- IDEALLY WE WOULD ALL FOCUS ON A PERSON'S STRENGTHS, CHALLENGES, AND NEEDS, AND LEAVE THE LABELS TO THE INSURANCE COMPANIES. HOWEVER, IT CAN BE A CONVENIENT SHORTHAND, IF WE TRUST THE PERSON LEARNING ABOUT THE LABEL.

## TIP: "HAS" VS. "IS"

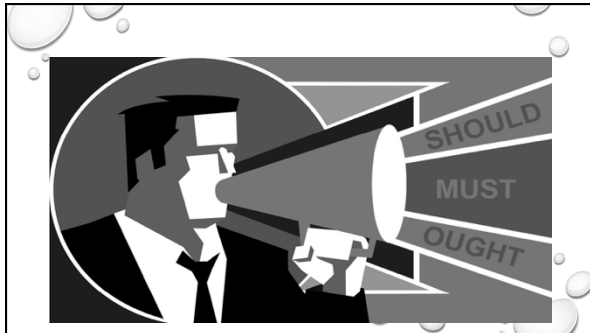
- WHEN WE SAY, "MY CHILD IS AUTISTIC," WE LEAVE OUT ALL OF THE OTHER SPECIAL, INTERESTING, AMAZING THINGS ABOUT HIM OR HER.
- WHEN WE SAY, "MY CHILD HAS AN AUTISM DIAGNOSIS," WE ARE DESCRIBING ONE PARTICULAR ASPECT OF THIS CHILD, ACKNOWLEDGING THAT OTHER TRAITS (SLEEPING LATE, LIKING PIZZA, SLEEPING NEXT TO THE PET) ARE IMPORTANT PARTS AS WELL.
- WE WOULDN'T SAY, "MY CHILD IS A LEGO FAN," OR "MY CHILD IS A NON-EATER OF SPINACH."
- AUTISM IS A CONDITION, NOT A COMPLETE IDENTITY.

## LIMITS VS. RISKS

- ALL CHILDREN HAVE LIMITS IMPOSED ON THEM BY THE WORLD AROUND THEM. WE CANNOT ALL BE ROCK STARS, ASTRONAUTS, STAR ATHLETES, OR SURGEONS.
- ACKNOWLEDGING AN ACTUAL HARD LIMIT DOES NOT AUTOMATICALLY LEAD TO DISCOURAGING THE CHILD.
- ENCOURAGING REASONABLE, HEALTHY, SAFE RISKS IS THE JOB OF PARENTS.
- DISCOURAGING RISK AND SENDING THE MESSAGE TO STOP TRYING – IF IT HAPPENS AT ALL – CAN OCCUR OUTSIDE OF THE FAMILY.

## "SHOULD" IS A FOUR-LETTER WORD

- PRECONCEIVED NOTIONS OF WHAT A PERSON'S DEVELOPMENT AND BEHAVIOR "SHOULD" LOOK LIKE ARE UNAVOIDABLE.
- IDENTIFYING THESE PRECONCEIVED NOTIONS – AND ACKNOWLEDGING THEM AS IRRATIONAL, UNHELPFUL, AND POTENTIALLY HARMFUL – MOVES US CLOSER TO ACCEPTANCE.
- MEETING OUR CHILD WHERE HE OR SHE IS, AND HELPING IN WAYS THAT WORK FOR US AND FOR THE CHILD, LETS THEM KNOW WE SEE AND ACCEPT THEM AS THEY ARE
- PARENTAL LOVE, ATTENTION, ACCEPTANCE, AND SUPPORT CAN BE **UNCONDITIONAL**



### TIP: ASK QUESTIONS

- WE WANT OUR CHILDREN TO AIM HIGH, BUT NOT WASTE THEIR TIME WITH AN IMPOSSIBLE DREAM
- WHEN WE SAY "YOU ARE NOT STRONG/SMART/FOCUSSED/TALENTED ENOUGH..." WE TELL OUR CHILD THAT THE PERSON THEY SEE THEMSELVES AS IS INVISIBLE TO US
- WHEN WE APPROACH WITH CURIOSITY ("HOW WILL THAT JOB PAY YOUR BILLS?" "DO YOU THINK YOU HAVE ENOUGH TIME TO PUT IN ALL THOSE HOURS OF PRACTICE?" "DO YOU WANT MY HELP?"), WE OFFER SUPPORT AND GUIDANCE, NOT CRITICISM OR DISMISSAL

### PUSHING: IF, WHEN, AND HOW HARD?

- MOST PEOPLE HAVE GOALS FOR THEMSELVES, AND ARE ABLE (EVENTUALLY) TO REALIZE WHEN OR WHETHER TO CHANGE TACTICS, OR TO ABANDON THE GOAL ENTIRELY
- THE OUTSIDE WORLD (SCHOOLS, EMPLOYERS, ETC.) PUSHES US PLENTY
- HOME CAN BE THE PLACE WHERE THEY ARE ACCEPTED AS THEY ARE, NOT "ALMOST" OR "IF"
- BEING PATIENT AND WAITING (FOR THE CHILD TO WORK HARDER, TO LEARN A NEW SKILL, TO CHANGE THEIR PLANS OR GOALS) IS **NOT** THE SAME AS DOING NOTHING
- IF MY CHILD SEEMS "LOST" OR "UNMOTIVATED" MY ROLE IS TO **HELP** THEM UNDERSTAND WHAT THEY WANT, AND TO HELP THEM GET IT, NOT TO URGE OR PUSH

### ABILITY CONFUSION

- MANY OF US – IN OUR THINKING AND IN OUR SPEECH – USE WORDS LIKE **IQ, INTELLIGENCE, ABILITY, CAPABILITY, AND FUNCTIONING** INTERCHANGEABLY, TO EVERYONE'S DETRIMENT
- THE ABILITY TO SOLVE SOPHISTICATED MATH PROBLEMS, PLAY A MUSICAL INSTRUMENT, DRIVE A CAR, OR BUILD A ROBOT ARE UNRELATED TO EACH OTHER AND OTHER TASKS
- IF MY CHILD UNDERSTANDS CALCULUS, BUT HAS DIFFICULTY DRESSING OR FEEDING HIMSELF, I NEED TO PLAN FOR THE FUTURE (AND ASSIST IN THE PRESENT) ACCORDINGLY
- 12<sup>TH</sup> GRADE IS MUCH MORE LIKE 1<sup>ST</sup> GRADE THAN IT IS LIKE COLLEGE



### THE CURSE OF "PASSING"

- SOME PEOPLE WITH AN ASD DIAGNOSIS PRESENT THE DISORDER IN MORE SUBTLE, LESS OBVIOUS WAYS
- ASSUMING THAT A PERSON'S ABILITY TO "APPEAR" "NORMAL" IS A STRENGTH THAT EXTENDS TO OTHER ASPECTS OF LIFE IS A MISTAKE
- GETTING THROUGH THE DAY WITHOUT BEING SEEN AS "ODD" OR "WEIRD" CAN BE EXHAUSTING, BOTH MENTALLY AND PHYSICALLY
- HOME CAN BE THE PLACE TO BE UNCONCERNED ABOUT APPEARANCES, AND TO REST

### COMORBID CONDITIONS

- DEPRESSION, ANXIETY, OBSESSIVE COMPULSIVE DISORDER, AND OTHER CONDITIONS OFTEN CO-OCCUR WITH PEOPLE ON THE SPECTRUM
- IDENTIFYING WHAT IS A SYMPTOM OF ASD, AND WHAT IS SOMETHING ELSE, CAN BE CHALLENGING
- THE BETTER I KNOW MY CHILD, THE EASIER IT IS TO KNOW WHEN SOMETHING HAS CHANGED FOR THE WORSE, OR IS "OFF"
- BEING OPEN TO OTHER ISSUES MEANS AN INCREASED CHANCE OF PROVIDING THE BEST TREATMENT

### A DIFFERENT PERSPECTIVE

- A GROWING NUMBER OF PEOPLE BOTH WITH AND WITHOUT THE DIAGNOSIS HAVE COME TO SEE ASD, IN ITS Milder MANIFESTATIONS, AS MORE OF A DIFFERENCE THAN A DISABILITY
- RATHER THAN CONCEIVE OF THE AUTISTIC BRAIN AS BROKEN OR SICK, WE CAN VIEW THE PERSON WITH AN ASD DIAGNOSIS AS SIMPLY A DIFFERENT KIND OF PERSON, WITH A DISTINCT WAY OF PERCEIVING AND INTERACTING WITH THE WORLD
- WHEN WE ARE ABLE TO SEE SOMEONE'S EXPERIENCE AS OTHER, RATHER THAN DEFECTIVE OR FLAWED, WE ARE ABLE TO SEE OUR OWN BELIEFS AS MORE FLEXIBLE AND SUBJECT TO CHANGE

### A child with autism -or- an autistic child?

The infographic is divided into two columns. The left column, titled 'The signs of Autism..', lists various behaviors such as 'Inconsistent eye contact', 'Inconsistent response to name', 'Inconsistent response to touch', 'Inconsistent response to sound', 'Inconsistent response to sight', 'Inconsistent response to taste', 'Inconsistent response to smell', 'Inconsistent response to temperature', 'Inconsistent response to pain', 'Inconsistent response to pressure', 'Inconsistent response to vibration', 'Inconsistent response to movement', 'Inconsistent response to sound', 'Inconsistent response to sight', 'Inconsistent response to taste', 'Inconsistent response to smell', 'Inconsistent response to temperature', 'Inconsistent response to pain', 'Inconsistent response to pressure', 'Inconsistent response to vibration', 'Inconsistent response to movement'. The right column, titled 'The reality of Autism..', lists various challenges such as 'Inconsistent eye contact', 'Inconsistent response to name', 'Inconsistent response to touch', 'Inconsistent response to sound', 'Inconsistent response to sight', 'Inconsistent response to taste', 'Inconsistent response to smell', 'Inconsistent response to temperature', 'Inconsistent response to pain', 'Inconsistent response to pressure', 'Inconsistent response to vibration', 'Inconsistent response to movement'. At the bottom, there is a logo for 'LIVING AMONGST AUTISTS' and the text 'www.livingamongstautists.com'.

### PARENTING AND SELF-ACCEPTANCE

- AS PARENTS OR CAREGIVERS, WE OFTEN ALLOW OUR OWN CONCEPT OF SELF TO BE DEPENDENT UPON THE SUCCESS OF OUR CHILD. ANY PROBLEM, MISSTEP, WRONG TURN, OR POOR CHOICE BECOMES A REFLECTION OF WHO WE, AS ADULTS, ARE, AND OF WHAT WE ARE WORTH. WHEN THIS HAPPENS, THE PRESSURE FOR THE CHILD TO SUCCEED INCREASES EXPONENTIALLY, AND WE BECOME MORE LIKELY TO MAKE UNWISE CHOICES. THE MORE COMFORTABLE I AM WITH MYSELF AS A FLAWED, ERROR-PRONE, CONFUSED, OFTEN IRRATIONAL WORK IN PROGRESS, THE MORE I AM ABLE TO RELAX INTO ACCEPTANCE OF THE SAME SHORT-COMINGS OF THOSE I CARE FOR.
- "I AM IMPERFECT AND WORTHWHILE, AS IS EVERYONE ELSE IN MY LIFE."

### SUPPORT IS ESSENTIAL

- THE BELIEF THAT A PERSON OR FAMILY IS CAPABLE OF SOLVING EVERY PROBLEM ENCOUNTERED WITHOUT HELP IS BOTH FALSE AND HARMFUL
- THE MORE CONTACT WE HAVE WITH OTHERS FACING THE SAME STRUGGLES, THE MORE MANAGEABLE AND UNDERSTANDABLE OUR CHALLENGES BECOME
- THE MORE COMFORT AND ACCEPTANCE WE EXPERIENCE WHEN WE REACH OUT TO OTHERS, THE MORE WE WILL RECEIVE IN RETURN, AND VICE VERSA
- SHAME IS A GREAT HINDRANCE TO ACCEPTANCE, BUT THE OPPOSITE IS ALSO TRUE. ACCEPTANCE CAN BE A SHIELD THAT KEEPS SHAME TO A MINIMUM.