

The slide features a light gray background with several realistic water droplets of various sizes scattered across it. A solid blue vertical bar is positioned on the far left side. The main title is centered in the upper half of the slide.

MAMA BEAR:

ENGAGING FAMILIES OF YOUNG CHILDREN WITH DISABILITIES.

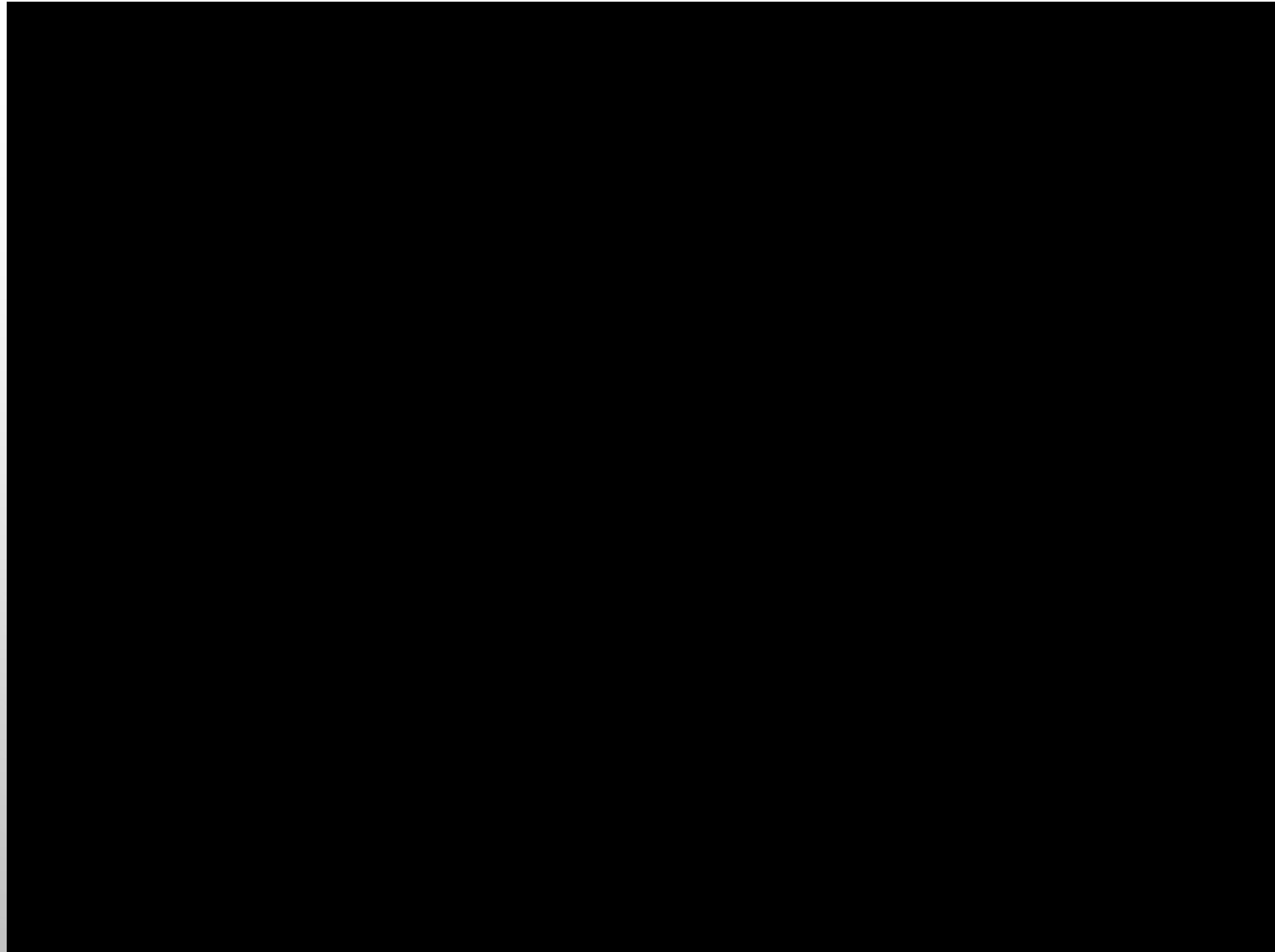
PRESENTED BY: EL BROWN, PH.D.

MEET THE PARENTS

- WE CAN LEARN ABOUT FAMILIES THROUGH THE NARRATIVES OF PARENTS.
- PARENTS OF CHILDREN WITH DISABILITIES HAVE BEEN DESCRIBED AS PRACTICAL SCIENTISTS AND CO-THERAPISTS, WHO TAKE AN ACTIVE ROLE IN EDUCATING AND RAISING THEIR CHILDREN WHILE BECOMING SKILLED AT SELECTING APPROPRIATE INTERVENTIONS (LOUKISAS & PAPOUDI, 2016).
- PARENTS AND SERVICE PROVIDER SHARE MUCH IN COMMON.



BILL DAVIS AND HIS SON, CHRIS



INDIVIDUAL & GROUP THINK

MEET BILL DAVIS AND HIS SON CHRIS

- WHAT DID YOU EXTRACT FROM THIS SHORT VIDEO?
 - CHARACTERISTICS?
 - EMOTIONS?
 - ROLES?
 - ACTIONS?
 - WANTS?



HIDDEN RESPONSIBILITIES

- ALL THE LITTLE EXTRA TASKS AND THOUGHTS THAT PARENTS OF CHILDREN WITH DISABILITIES HAVE TO EMPLOY DURING THE DAY TO ENSURE OUR HOME, LIFE, AND CHILD REMAIN BALANCED.
- THESE ARE TASKS THAT THE WORLD DOESN'T SEE BECAUSE THEY ARE HIDDEN; EMBEDDED INTO THE EXPERIENCE OF PARENTING A CHILD WITH DISABILITIES.



MEET PARENTS WHERE THEY ARE

GRIEF (EMOTIONAL PROCESS)

- RESPONSE TO A LOSS.
- EMOTIONAL SUFFERING FELT WHEN SOMETHING OR SOMEONE YOU LOVE IS TAKEN AWAY.
- IN 1969, PSYCHIATRIST ELISABETH KÜBLER-ROSS INTRODUCED WHAT BECAME KNOWN AS THE “FIVE STAGES OF GRIEF.”

AWARENESS (COGNITIVE PROCESS)

- KNOWLEDGE OR PERCEPTION OF A SITUATION OR FACT.
- WE ALL HAVE OUR OWN LEVEL OF TRUTH OR AWARENESS, AND OFTEN WE ARE UNAWARE OF THE PERSPECTIVE OR ATTITUDES OF OTHERS (SCHAEF, 1992).
- ULRICH AND BAUER IDENTIFIED AND DESCRIBED FOUR LEVELS OF AWARENESS, IN 2003.



STAGES OF GRIEF

- **DENIAL:** “THIS CAN’T BE HAPPENING TO ME.” [L] [SEP]
- **ANGER:** “WHY IS THIS HAPPENING? WHO IS TO BLAME?” [L] [SEP]
- **BARGAINING:** “MAKE THIS NOT HAPPEN, AND IN RETURN I WILL ____.” [L] [SEP]
- **DEPRESSION:** “I’M TOO SAD TO DO ANYTHING.” [L] [SEP]
- **ACCEPTANCE:** “I’M AT PEACE WITH WHAT HAPPENED.”



LEVELS OF AWARENESS

- **OSTRICH PHASE (YOU DON'T KNOW WHAT YOU DON'T KNOW):** THE FIRST LEVEL OF AWARENESS IS ACTUALLY A LACK OF AWARENESS.
- **SPECIAL DESIGNATION ("AHA" PHASE):** THE SECOND LEVEL OF AWARENESS OCCURS WHEN PARENTS HAVE, THROUGH SOME TRANSFORMATIONAL EXPERIENCE, RECOGNIZE THAT THERE IS INDEED A DISABILITY.
- **NORMALIZATION (HOPE IGNITED):** DURING THE THIRD PHASE, PARENTS MINIMIZE DIFFERENCES BETWEEN THEIR CHILD AND HIS OR HER CLASSMATES AND SIBLINGS.
- **SELF-ACTUALIZATION (DIFFERENT NOT LESS THAN):** THE FOURTH LEVEL OF AWARENESS OCCURS WHEN PARENTS RECOGNIZE THAT CHILD WITH DISABILITIES NEED SUPPORTS



CULTURAL HUMILITY

- A PROCESS OF REFLECTION AND LIFELONG INQUIRY, INVOLVES SELF-AWARENESS OF PERSONAL AND CULTURAL BIASES AS WELL AS AWARENESS AND SENSITIVITY TO SIGNIFICANT CULTURAL ISSUES OF OTHERS.
- DOES NOT ASSUME THAT WE CAN EVER KNOW ENOUGH ABOUT SOMEONE ELSE'S EXPERIENCES TO BE COMPLETELY COMPETENT.



INDIVIDUAL & GROUP THINK

WHAT PARENTS WANT FROM YOU

- DIVIDE INTO GROUP OF 4 OR 5
- DISCUSS AND RECORD YOUR TOP 3 ANSWERS FOR THE FOLLOWING QUESTIONS.
 1. WHAT DO PARENTS OF CHILDREN WITH DISABILITIES CONSIDER THE MOST HELPFUL ACTIONS BY SERVICE PROVIDERS?
 2. WHAT SERVICE PROVIDERS ARE SEEN AS MOST HELPFUL BY PARENTS OF CHILDREN WITH DISABILITIES?
 3. WHAT DO PARENTS OF CHILDREN WITH DISABILITIES CONSIDER THE MOST UNHELPFUL ACTIONS BY SERVICE PROVIDERS?
 4. WHAT DO PARENT OF CHILDREN WITH DISABILITIES WANT FROM YOU?



HELPFUL ACTIONS

Table 1. Helpful actions performed

Helpful action specified by parents	Frequency	Total (%)
Performed one's job well	44	40.7
Supported parent and/child	16	14.8
Encouraged Inclusion	14	13.0
Enhanced self-esteem of child	8	7.4
High expectations for child	8	7.4
Went beyond 'required' job duties	7	6.5
Teach parents	4	3.7
Necessary accommodations for child	4	3.7
Engaged in advocacy	2	1.9
Learned from parents	1	0.9
Total	108	100

PROFESSIONALS SEEN AS HELPFUL

Table 2. Professionals identified as performing helpful actions

Professionals	Frequency	Total (%)
Teachers	42	37.5
Allied health professionals	24	21.4
Early intervention specialists	14	12.5
Other	13	11.6
Mental health professional	10	8.9
Principals	5	4.5
Physicians	4	3.6
Total	112	100

UNHELPFUL ACTIONS

Table 3. Unhelpful actions performed

Unhelpful actions specified by parents	Frequency	Total (%)
Poor performance of job	25	23
Low expectations	21	19.4
Noncompliance with regulations and recommendations	14	13
Discouraged Inclusion	11	10.2
Demeaned parent or child	9	8.3
Abused power	7	6.5
Ignored parental input	6	5.6
Recommended institutionalization	3	2.8
Physical abuse	2	1.9
No unhelpful actions	6	5.6
No response	4	3.7
Total	108	100

DESIRED ACTIONS

Table 5. Actions parents would like professionals to take

Desired actions	Frequency	Total (%)
Listen/respect parent input	24	20%
Be competent and provide information	23	19%
Collaborate/communicate	15	13%
Long-term future	14	12%
Skill development including social	14	12%
Focus on person	8	7%
Provide appropriate accommodations	7	6%
Empower and support	6	5%
Follow through on job functions	5	4%
Other	4	2%



COMMUNICATION

- BE INFORMED
- POSITIVE, TACTFUL AND SENSITIVE
- STRENGTH-BASED PERSPECTIVE
- AVOID JARGON
- RESPECTFUL & PEOPLE FIRST TERMINOLOGY; AVOID “NORMAL”
- RECOGNIZE FAMILY AS EXPERTS
- TWO-WAY DISCUSSION, ALLOW TO EXPRESS HOPES AND DREAMS
- PROVIDE DOCUMENTATION
- TRANSLATE
- PART OF DECISION MAKING PROCESS
- PROVIDE OPPORTUNITIES FOR FAMILIES TO LEARN ABOUT THE DIFFERENT SERVICES/SERVICE PROVIDERS
- COORDINATION OF SERVICE PROVIDERS



LET'S KEEP THIS LEARNING PARTY GOING!



CONNECT WITH ME! WE'RE FRIENDS NOW!

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