

# the FUTURE of CARE for CHILDREN with MEDICAL COMPLEXITY

## CAFE Z: HUMANISM in CLINICAL CARE to MEET WHOLE CHILD/FAMILY NEEDS

HUMAN EXPERIENCES, VALUES, & DIGNITY ARE FIRST & FOREMOST



WHAT FAMILIES TOLD US MATTERS MOST for HUMANISM in CARE:

UNDERSTANDING WHAT MATTERS TO PATIENTS & FAMILIES

WHAT TECHNIQUES, STRATEGIES, & TOOLS CAN WE DRAW UPON to OPERATIONALIZE HUMANISM in CARE?

WHAT CHANGES NEED to HAPPEN to BETTER INTEGRATE ELEMENTS of HUMANISM INTO CARE?

SOCIETAL BIAS  
"THE SYSTEM HAS SHORTCOMINGS... NOT the CHILD"

WHAT HUMANISM LOOKS LIKE to FAMILIES:



- RELATIONSHIP & TRUST
- CREATIVITY for WHOLE CHILD
- PARTNERSHIP & COMMUNICATION FOR PROVIDERS:
- POWER of FAMILY-to-FAMILY SUPPORT

DEVELOPING AUTHENTIC RELATIONSHIPS: TRUST & RESPECT!

TREATING PATIENTS & FAMILIES as WHOLE PEOPLE (NOT JUST a DIAGNOSIS)

PROVIDING INDIVIDUALIZED, WHOLE-PERSON CARE ALIGNED with FAMILY GOALS & PRIORITIES



ACTIVE LISTENING & HUMBLE INQUIRY

NARRATIVE TOOLS to UNDERSTAND FAMILY PERSPECTIVE

FLEXIBLE CARE DELIVERY to MEET FAMILY NEEDS

MULTIDISCIPLINARY TEAMS that INCLUDE FAMILIES AS PARTNERS

REDESIGNING SYSTEMS to ENABLE RELATIONSHIP-CENTERED CARE.

TRAINING PROVIDERS: START EARLY in their EDUCATION

TRANSFORMING CULTURE & MINDSETS ACROSS ALL MEMBERS of the CARE TEAM

### KEY IDEAS from BREAKOUT DISCUSSIONS

POWER of STORIES

- \* BUILT TRUST by LISTENING
- \* AFFIRMATION for PARENTS' LOVE & JOY for their CHILD



\* COMPETING PRIORITIES: DETRIMENTAL BUT ALSO NECESSARY to PUSH US

\* PRESUMPTION of CONFIDENCE. RECOGNIZE the EXPERTISE in the ROOM!



\* THE POWER of LISTENING

JOY COMES FROM EARNING the TRUST of FAMILIES!



HEALTHCARE is GOOD at DEHUMANIZING CARE...

