

the FUTURE
of CARE

FOR CHILDREN with
MEDICAL COMPLEXITY

CAFÉ 4

FAMILY-DRIVEN APPROACH to UNDERSTAND FAMILY WELL-BEING & ITS FACILITATORS



Nikki Montgomery

PARENT of a
MEDICALLY COMPLEX
13-YEAR-OLD!

FAMILY WELL-BEING

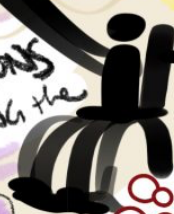
COMPLEXITY — RICH,
AUTHENTIC
FAMILY
ENGAGEMENT
PROCESS

NOT JUST
GETTING
CARE... IT'S ABOUT
QUALITY
CARE

300 FAMILIES

800+ IDEAS!

MAKE
TRANSITIONS
EASY



FOCUS ON WHOLE
FAMILY WELL-BEING

Lucile Packard
Foundation

Children's Health

KATIE HUTH



CARING for the CHILD MEANS
CARING ABOUT the FAMILY,
& PARTNERING with
FAMILIES as COLLEAGUES.

ASKING the
RIGHT
QUESTIONS

THERE IS NOT
ONE
RIGHT ANSWER

WITH
FAMILIES

BREADTH
and
DEPTH

EVERY
VOICE
COUNTS

JAY BERRY



How CAN WE ACTUALLY
IMPLEMENT our FINDINGS?



BEYOND
ACADEMIC
PUBLICATIONS

KEY IDEAS from
BREAKOUTS:

MEDICAL
PROFESSIONALS'
PREP &
COMMUNICATION

CHART
AHEAD of
TIME

WHAT IS
FEELING
HARD for
YOUR FAMILY
RIGHT NOW?

COMMUNICATION
SKILLS

IMPROVING
PROFESSIONAL
EDUCATION
through

Stories

MEANINGFUL WAYS
of ASSESSING FAMILY
WELL-BEING?

THIS WORK IS
DYNAMIC

AND these ISSUES
are LONG-STANDING

ADDRESSING
TRAUMA

IMPROVING
POLICY

IDENTIFY
INADEQUACIES

DIAPER
CHOICES

TRAINING
on
ASSESSMENT

WHAT IS
NOT
BEING SAID

PROMOTE DIVERSITY in
PROFESSIONAL EDUCATION

WAYS to EDUCATE/
BUILD AWARENESS?

GETTING INFO to
FAMILIES WHERE
they ALREADY
ARE

SHORT
FACTUAL
VIDEOS

FOLLOW-UP
AFTER
ASSESSMENT

SUPPORT
SYSTEM

MAKING INFO
ACCESSIBLE

FAMILY TRACKS
at CONFERENCES!

FAMILY
TRACK

Illustrated by
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CONVERSKETCH.COM