Mental Health and Therapeutic Considerations for Serving Children with Chronic Health Conditions

Larry L. Mullins, Ph.D.
Regents Professor
Center for Pediatric Psychology
Department of Psychology
Oklahoma State University

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THE CONTEXT OF CHRONIC HEALTH CONDITIONS IN CHILDREN AND THEIR FAMILIES

- WHAT DO THE NUMBERS TELL US?
- THIS A NEGLECTED AND OFTEN OVERLOOKED POPULATION
- OBVIOUS GAPS IN OUR TRAINING PROGRAMS EXIST, DESPITE THESE COMPELLING NUMBERS

THE CONTEXT

- Ever evolving medical technology over the past 100 years has resulted in ***growing numbers of children who are diagnosed earlier and earlier with a chronic health condition, and who are living longer, with more intensive treatments.***
- **Increasing prevalence, along with increasing survival rates.** Examples: pediatric cancer (cure rates exceeding 90% for some forms of leukemia), sickle cell disease (median survival age 14 in 1960, now between 42 and 47), cystic fibrosis (median survival age went from 11 in 1966 to 30 in 1993 to 46 years in 2022).

THE CONTEXT

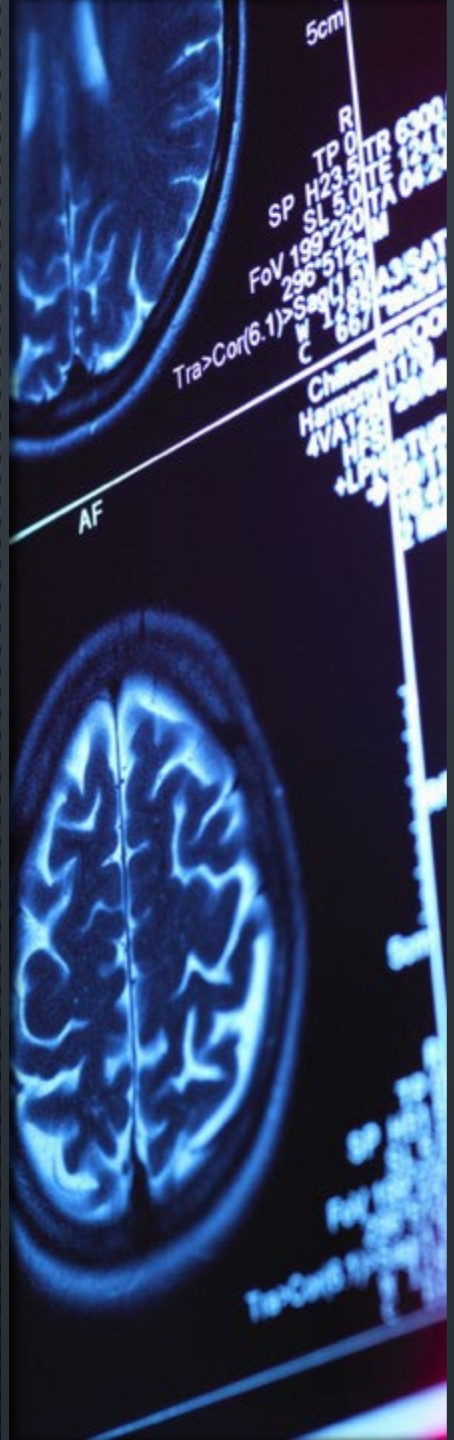
- **OTHER CONTRIBUTORS:** PREMATURE INFANTS SURVIVING EXTREME PREMATURITY OR LOW BIRTH WEIGHT. HAVE SEEN A PROGRESSIVE DECLINE IN MORTALITY. HOWEVER, RATES OF SUBSEQUENT HANDICAPPING CONDITIONS HAS REMAINED RELATIVELY STABLE.
- INCREASED PREVALENCE OF **NEW CONDITIONS**: HIV, SUBSTANCE EXPOSED YOUTH. THESE YOUTH PRESENT WITH A VARIETY OF NEURODEVELOPMENTAL PROBLEMS.

EPIDEMIOLOGY OF HEALTH CONDITIONS

- So what do we know?
- Rates of children with a chronic health condition range from 10-20 per cent, with 10 per cent being classified as **severe**.
- 1-2 per cent have severe conditions that may regularly interfere with daily activities, including school, play, and chores. This may be translated into about 2 million children.
- As many as one third of these conditions may be considered "permanent".

Types of Chronic Health Conditions

- Asthma, Allergies, Type 1 and Type 2 Diabetes, Obesity, Cystic Fibrosis, Crohn's Disease/IBD, Pediatric Cancer, Migraines, Seizure Disorders, Kidney Disease, Liver Disease, Disorders of Sex Development, Autoimmune disorders including HIV, Sickle Cell Disease, Hemophilia, Traumatic Brain injury, Pain syndromes.
- Many of these Diseases are "Hidden". Many involve stigma.. Does not include "rare" diseases.
- Developmental Disabilities, including cerebral Palsy, Muscular Dystrophy, Spina Bifida, and a wide array of Genetic Disorders. Agina, may include prenatal Drug exposure and subsequent neurodevelopmental challenges

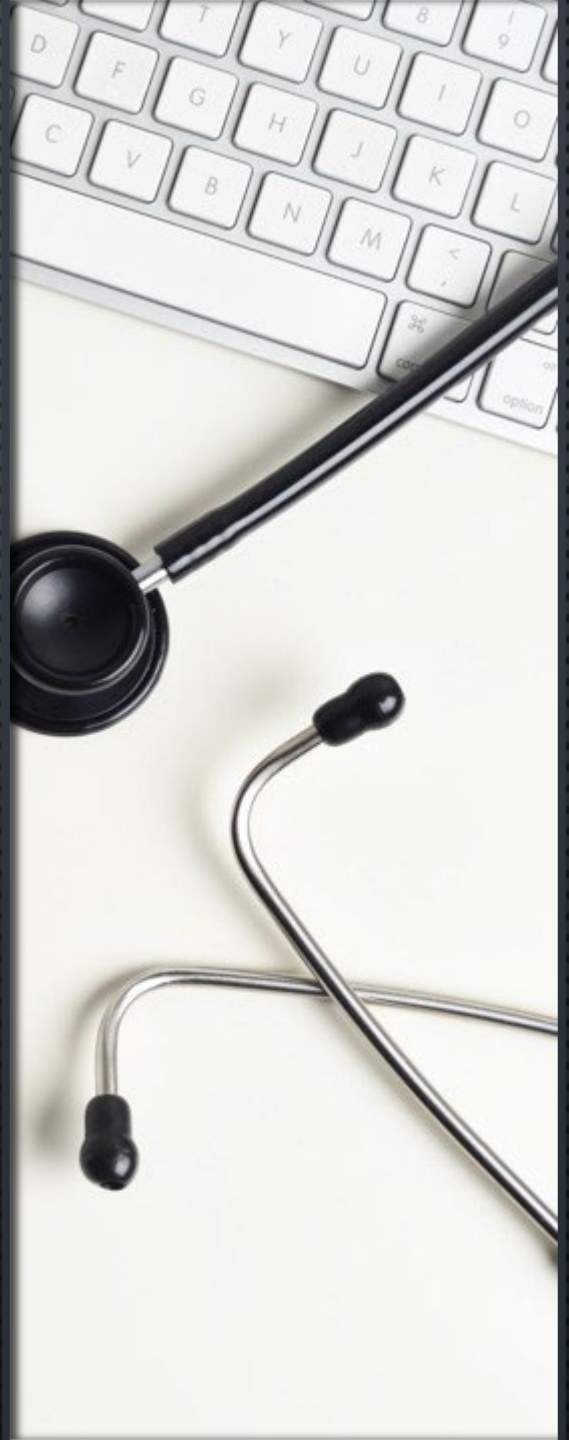


THE COSTS OF HEALTH CARE

- From **1996 to 2013**, overall healthcare spending on children increased from $149.6 **billion** to $233.5 (UI, 226.9-239.8) **billion**. In 2013, the largest health condition leading to health care spending for children was well-newborn care in the inpatient setting. Attention-deficit/hyperactivity disorder and well-dental care (including dental check-ups and orthodontia) were the second and third largest conditions, respectively (Bui et al, 2016).
- $9 billion of these dollars were spent on asthma alone.
- Lifetime care for Sickle Cell disease- $460,000 per person.

WHO NEEDS THERAPEUTIC SERVICES?

- RELIABLE DATE INDICATES THAT SOMEWHERE BETWEEN 25-33% OF THESE KIDS AND THEIR PARENTS HAVE CLINICALLY SIGNIFICANT LEVELS OF DISTRESS
- MANY HAVE "SUBCLINICAL" DISTRESS



SO WHAT ARE OUR GOALS HERE TODAY?

So what else do I want like to accomplish today:

1. Briefly describe the relevance of family systems frameworks and the integration of those frameworks into a biopsychosocial approach to pediatric health care.

2. Identify a range of evidence-based multilevel interventions for specific pediatric presenting problems, including new interventions that have emerged in the last two decades.

3. Demonstrate an understanding of family risk and resilience factors and how to take them into account in developing interventions.

4. Outline strategies for assessing and treating a range of presenting problems in the context of pediatric health using a family systems based, caregiver centered approach.

WHAT AM I REALLY GOING TO TRY TO DO?

- Sell you on the importance of working with families of children with a chronic health condition.

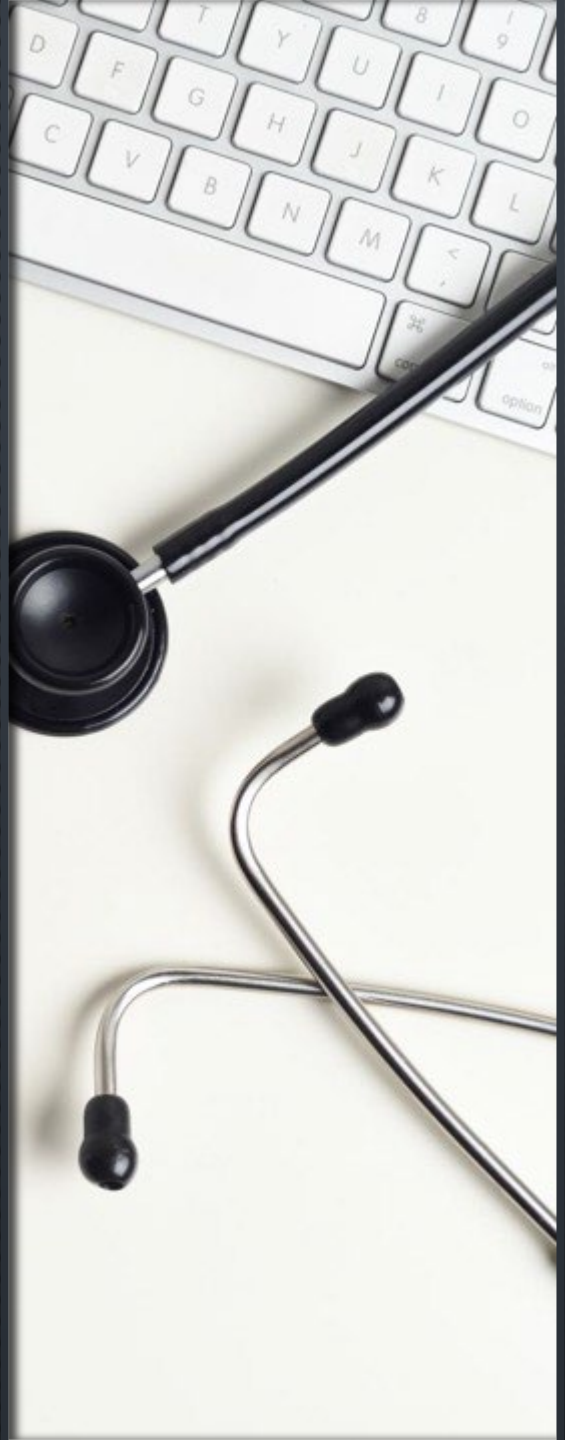
A NEW CALL FOR A FAMILY SYSTEMS CAREGIVER-CENTERED APPROACH TO PEDIATRIC HEALTH

We may have shifted our focus away from family centered approaches to Individually-based approaches

Training models have shifted

Telehealth , Apps, and Zoom may have only increased the focus on Individually focused care

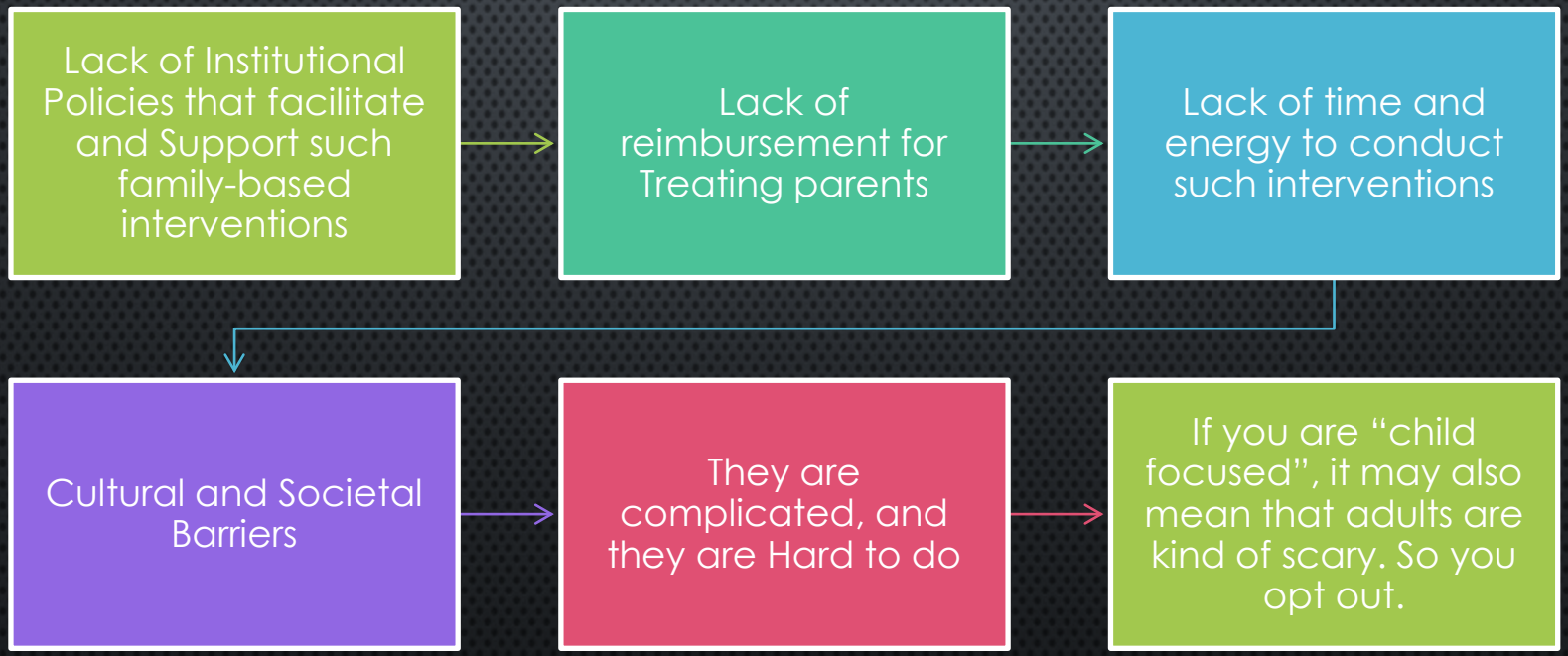
But the last time I checked, Kids do not exist in a vacuum.



Remember, in the context of pediatric health care….

- One of the single best predictors of child adjustment is Parent adjustment
- One of the single best predictors of treatment failures is the failure to understand the dynamics of the system and skillful, strategic inclusion of Parents /caregivers. And community partners.
- Bakula et al, 2019; Bakula et al, 2020

BARRIERS TO INSTITUTING SYSTEMIC APPROACHES AND WORKING WITH FAMILIES WITH A CHILD WITH A CHRONIC HEALTH CONDITION



DO WE HAVE AN ETHICAL AND MORAL IMPERATIVE TO INTERVENE SYSTEMICALLY?

- Systems, Parent centered C BT interventions work, and that has been documented through countless studies

FAMILY SYSTEMS MODELS

"A new way of looking at the nature of human problems…"

Basic Tenets:

1. **Systems exist as organizing structures at different levels of human behavior, including families and institutions**" (home, work, friends, book club, church, biker club).

2. **Each system has multiple interrelated parts, each with a history of interaction and an expectation of future interaction** (e.g., don't come home with purple hair)

FAMILY SYSTEMS-BASIC TENETS

3. **Systems seek a homeostatic balance; changes in one part of the system inevitably lead to changes in another part of the system** (e.g., diagnosis of a child with Type 1 is a stressor to which all must adapt. The system is disrupted. It must change.

4. **Rules, both implicit and explicit, govern all systems. Some allow for change, some exist to maintain order.** (e.g, "I am the breadwinner and I must work while you attend appointments"). Implicit rules may be the more "important" set of rules.

5. **Families inevitably change over time from a developmental perspective.**

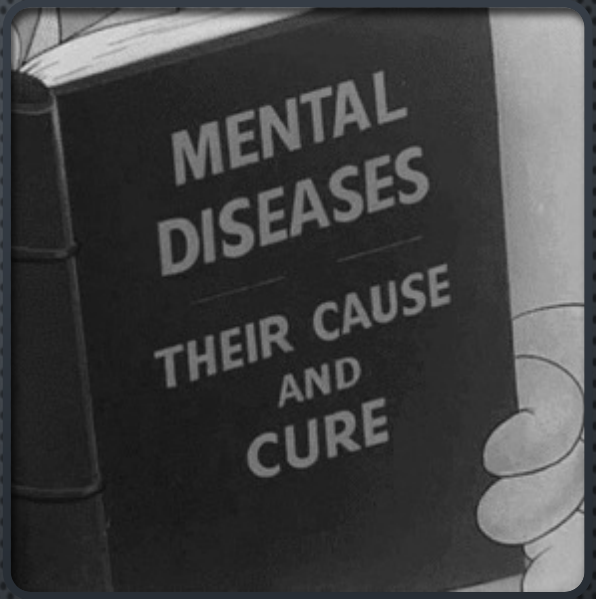
What happens to the concept of causality in such a model? Nonlinearity and bidirectional operate ….

FAMILY SYSTEMS-BASIC TENETS

So where does psychopathology "lie"? Historically, we have all been taught that it lies within the individual, like an insidious intrapsychic virus.

Jay Haley-a problem is defined as a type of behavior **that is part of a sequence of acts between several people.** A symptom is a label for such a sequence. *Symptoms are a contract between 2 or more people.*

Broadly speaking, a family systems view of behavior looks at the child's symptoms in maintaining the balance of relationships or equilibrium of the family.

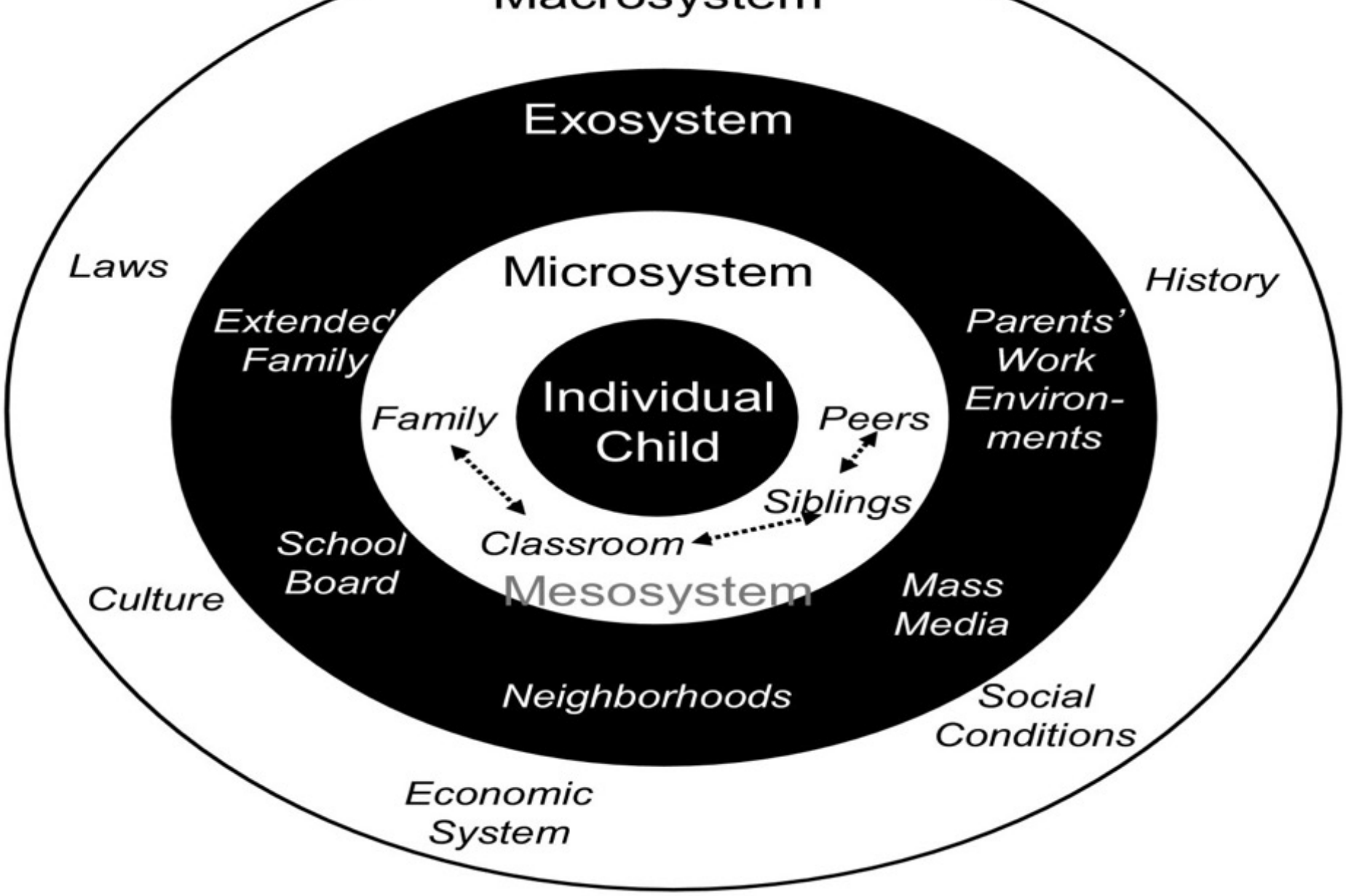


Family Systems Models

- ***Behavioral Systems Models-*** (Patterson, Henggeler and Borduin's Multisystemic Model). Focus on multiple level interventions taking into account biological factors, family influences, school and community.
- Why was this model important?
- Truly a biopsychosocial approach

Family Systems Models

- Meta analyses now support:
- Multisystemic Therapy
- Functional Family therapy
- Multidimensional family therapy
- Cognitive Behavioral Family therapy
- General Systemic family therapy
- Almost all of these Focus on multiple level interventions, taking into account both biological factors, family influences, school, and community Levels of influence.



SO, HERE ARE YOUR POTENTIAL TARGETS OF INTERVENTION! THIS IS YOUR "PLAYING FIELD".

TRANSTHEORETICAL CHANGE PRINCIPLES CENTRAL TO A FAMILY SYSTEMS, CAREGIVER-CENTERED APPROACHES

FRIEDLANDER, HEATHERINGTON, & DIAMOND, 2021

1. Develop a warm, genuine relationship with individuals, subsystems, and the family as a unit, taking into account each client's level of safety.

2 Strive to create a balanced therapeutic alliance with all members; avoid split alliances by constructing a non-blaming, systemic view of the presenting problems and underlying dynamics.

3. Clarify each members commitment to change" and "Nurture a shared sense of purpose". (Go for the emotional jugular vein. Make every person in the room cry).

KEY PRINCIPLES

4. Help family members imagine the personal and collective benefits by expressing optimism for the possibility of change"

5. Adapt evidence-based interventions that respect client's cultural diversity, being mindful of cultural variables, socioeconomics, immigration status, racism, sexism, heterosexism as well as the role of culture to family dynamics (hierarchy, power, boundaries, extended family members.

6. Work with subsystems to prepare them to collaborate on difficult issues. Adapt to their developmental and cognitive level, as well as their motivational level". (Motivational interviewing)

KEY PRINCIPLES

7. Strengthen boundaries between people and subsystems e.g., between parents and adolescents, between parents and nurses and physicians, etc.

8. Strive to change family members experience of each other (e.g., attachment ruptures, problem solving skills, conflict management). "Your father never had a father".

9. Orchestrate the acquisition of needed resources for individuals struggling with serious mental health or substance abuse issues.

KEY PRINCIPALS

10. Help family members consider alternate, more constructive attributions for each other's negative behaviors (and those of physicians, nurses, etc). Emphasize the strengths and positive characteristics of other individuals and subsystems.

11. Directly address dysfunctional and destructive behavior" (e.g., "I do not want this kid in my school system"

12. Respond sensitively and in a supported way to patients and families who feel blamed for their limitations". Often, we inadvertently blame the victim. And bad patients…..

PART II . SPECIFIC INTERVENTIONS IN PEDIATRIC HEALTH CONDITIONS WITH A FAMILY SYSTEMS CAREGIVER CENTERED APPROACH

- I'll be overviewing a number of interventions that have been developed in the Pediatric medical Context. Some are illness-specific, some are more generally focused across Illnesses/ Health conditions.
- Many are Integrated approaches, combining CBT and interpersonal approaches with family systems interventions.
- Many can be adapted so as to individually tailor the intervention to fit the needs of the family, their worldview, and your skillset and available resources. Think precision medicine!

SPECIFIC INTERVENTIONS IN PEDIATRIC HEALTH CONDITIONS: CONSIDERATIONS IN CHOOSING A TREATMENT- BROAD CONSIDERATIONS

What is the target problem (and associated goal) from the perspective of the child?

What is the target problem (and associated goal) from the perspective of the Parent (s)?

What are the unique qualities of the family that bear on risk and resistance? What are their Strengths and Challenges?

What are the Interpersonal and structural barriers to implementing treatment (Mental Health History, poverty, language, racism, developmental challenges, health literacy, institutional Policies, Insurance status)?

What Changes are taking place in the family structure and roles as a function of the Illness?

Who are the players across multiple points in their larger system? What are the subsystems?

SPECIFIC INTERVENTIONS IN PEDIATRIC HEALTH CONDITIONS: CONSIDERATIONS IN CHOOSING A TREATMENT

Examples:

Five-year old female newly diagnosed with ALL. Parents are recent immigrants from Nigeria. Six other siblings in the home. Currently underinsured. Mom and Dad are both medical Residents.

11-year-old previously diagnosed with ASD, 3 psychiatric hospitalizations. Referral from School wanting help with re-entry. Mom is working with advocate and BCBA, School has hired an attorney. Superintendent doesn't want the student in school. New special education director.

16-year-old w/ recent SCI riding a 4 wheeler in rural Oklahoma. Previous history of ADHD and learning disability. Parents have never been married and live separately. Grandmother is the primary caregiver.

WHAT PROGRAMS AND INTERVENTIONS DO WE HAVE AT HAND THAT WORK?

Family and Parent-Centered Interventions-Surviving Cancer Competently

- SCCIP- Surviving cancer competently/ Anne Kazak and Colleagues.
- Kazak has been hammering the family systems message home since 1997!
- One of the first family systems based psychosocial interventions for families of children diagnosed with cancer.

Family and Parent-Centered Interventions-Surviving Cancer Competently

- SCCIP-Targeting Newly diagnosed Kids
- Combines Cognitive behavioral and family therapy approaches in a three-session Group format
- In this intervention, Caregivers work conjointly in groups to identify beliefs about their experiences during the initial month of treatment, a time in which potentially traumatic events may occur.
- focus I on understanding how beliefs about cancer and its treatment influence caregivers and to help family members anticipate the impact of cancer on the family over time

FAMILY AND PARENT-CENTERED INTERVENTIONS-SURVIVING CANCER COMPETENTLY (2005)

- SCCIP-NEWLY DIAGNOSED INTERVENTION
- KEY CROSS CUTTING CONSTRUCTS: FOUR KEY CONSTRUCTS THAT CROSSCUT THE SESSIONS WERE IDENTIFIED:

(1) JOINING IS THE ONGOING PROCESS BY WHICH A THERAPIST RELATES TO FAMILY MEMBERS USING ACCEPTANCE, RESPECT, CURIOSITY, AND HONESTY

(2) **MAINTAINING AN INTERPERSONAL FOCUS** ASSURES THAT CAREGIVERS FOCUS ON HOW THEIR EFFECTIVE COPING HELPS THEIR CHILD'S ADAPTATION.

(3) **NORMALIZING THE FAMILY EXPERIENCE.** HELPFUL IN DECREASING FEELINGS OF ISOLATION AND ANXIETY.

(4) **FOCUSING ON THE FAMILY'S STRENGTHS.** REFLECTS THE PERSPECTIVE THAT PARENTS AND FAMILIES ARE COMPETENT, ABLE TO ADAPT TO ADVERSE CIRCUMSTANCES, AND TO CONTINUE GROWING AND DEVELOPING AS A FAMILY DESPITE THEIR CHILD'S ILLNESS.

Family and Parent-Centered Interventions

- **Problem Solving Therapy (PST) for parents of children diagnosed with Cancer-The Bright Ideas Program** (Sahler, Phipps, Dolgin, Fairclough, Askins, Katz, Noll, & Butler, 2005; 2013
- One of the interventions with the most empirical support to date
- Target Audience: parents of Children Newly Diagnosed with Cancer
- Key therapeutic component: Problem Solving therapy

PROBLEM SOLVING THERAPY

Problem Solving Therapy (PST)

Core components: Delivery of the content of PSST includes:

Session 1: rapport building and understanding, relevant personal background and medical information;

Session 2: introduction of PST and the Bright IDEAS paradigm;

Sessions 3 to 7: review of the mother's identified problems and promotion of problem-solving strategies and skill;

Session 8: review of PST, identification of relapse prevention strategies (e.g., persistence, learned optimism), and termination.

PROBLEM SOLVING THERAPY

- Efficacy: Demonstrated decreases in negative affectivity (depressive, anxious and Post traumatic symptoms), increases in problem solving skill
- some indication that mothers most at risk (young, single, Hispanic moms) may benefit the most
- Easily taught/manualized (available at NIH/NCI National Registry of Evidence based interventions).
- Easily adapted for many target populations, including sickle Cell disease

FAMILY AND PARENT-CENTERED INTERVENTIONS-PRISM-P

- Abby Rosenberg's **PRISM-P intervention: Promoting Resilience in Stress Management Intervention for Parents of children with Cancer** (Rosenberg, Bradford, Junkins, Taylor, Zhou, Sherr, Kross, Curtis, & Frazier (2019).
- Authors Underscore the relative lack of evidence-based interventions for parents.
- Prism-P is a Manualized , brief intervention targeting 4 skills: **stress management** (including relaxation and mindfulness Training), **goal setting Skills** (including tracking progress, **cognitive reframing** (recognizing negative self talk and cognitive reappraisal, and **meaning-making** (identifying gratitude, meaning and purpose despite adversity).
- **Focus is on Positive psychology concepts and resiliency!**
- Targets Parents of Patients newly diagnosed with Cancer.

FAMILY AND PARENT-CENTERED INTERVENTIONS -IMPACT

- IMPACT-AN UNCERTAINTY-BASED INTERVENTION FOR PARENTS OF YOUTH NEWLY DIAGNOSED WITH CANCER

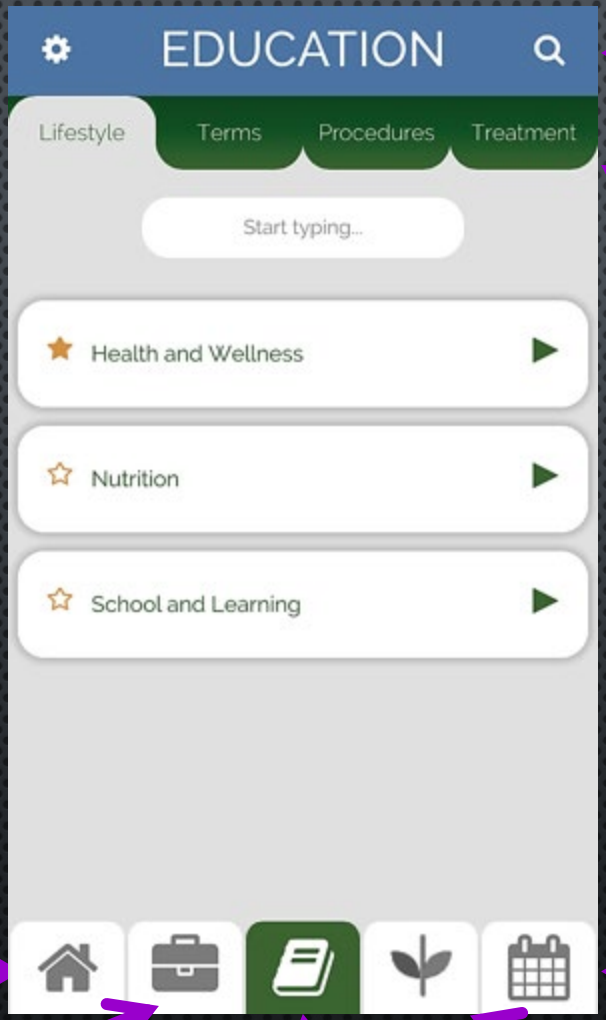
IMPORTANCE OF ILLNESS UNCERTAINTY

- Over and over again, illness uncertainty has been shown to be a *highly salient and robust predictor of multiple adjustment outcomes* in both adult and child chronic illness populations, including pediatric cancer, adult cancer, JRA, pediatric asthma, among many, many others (e.g. Hoff, Mullins, Chaney, Hartman, & Domek, 2002; Gillaspy, Hoff, Mullins, Van Pelt, & Chaney, 2002; White et al., 2005; Grootenhuis & Last,1997; Stewart & Mishel, 2000).
- **Arguably, if you can teach parents and youth to cope with and manage uncertainty, distress should be attenuated.**
- ***Thus, uncertainty becomes the target.***

UNCERTAINTY INTERVENTION DEVELOPMENT

- AN INITIAL VERSION OF A PSYCHOSOCIAL INTERVENTION **WITH PARENTS** OF YOUTH NEWLY DIAGNOSED WITH TYPE 1 DIABETES WAS EVALUATED, WITH THE EXPLICIT AIM OF TEACHING THE PARENTS HOW TO MANAGE UNCERTAINTY. THEN ADAPTED TO THE CONTEXT OF PEDIATRIC CANCER, IN TWO SEPARATE TRIALS .
- INTERVENTION CONSIST OF COGNITIVE BEHAVIORAL STRATEGIES THAT TEACH:
  - THE NATURE OF UNCERTAINTY
  - COPING STRATEGIES
  - PROBLEM-SOLVING SKILLS
  - COMMUNICATION WITH THE MEDICAL TEAM
  - ELICITING SOCIAL SUPPORT
  - TARGET PARENTS OF CHILDREN NEWLY DIAGNOSED DURING THEIR REGULAR VISITS OR HOSPITALIZATION

APP DEVELOPMENT



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Family and Parent-Centered Interventions-MST

- What is Multlisystemic Therapy?
- In response to the disappointing outcome results for Family therapy in the 1970-80s, Henggeler and Borduin (1990) developed **multisystemic therapy**, based on a family ecological approach.
- Arguing against the sometimes narrow (and vague) perspectives of many family therapy models, they provided an integrative model that incorporated evidence-based Practice
- They also Noted the failure to address individual developmental differences and extrafamilial influences, such as the community

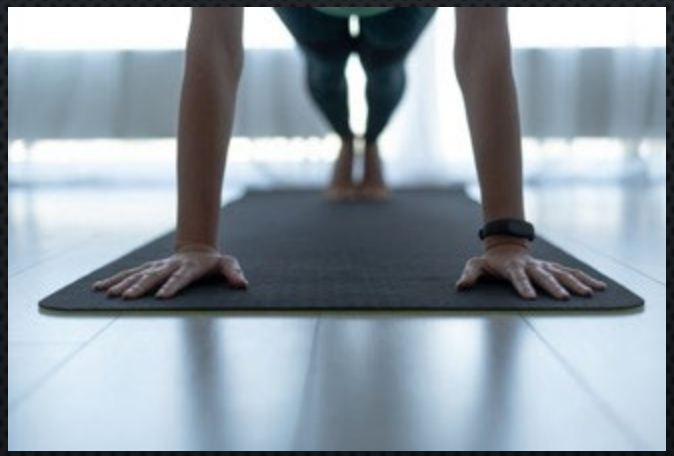
Family and Parent-Centered Interventions

- **Focus is on developing interventions that play upon strengths, not just deficits.**
- **Multisystemic intervention** Occurs at the individual level (e.g., cognitive Behavior therapy, medications), parent Level factors (e.g., parent training, Marital therapy), family Level (e.g., conflict resolution), school system (e.g., teacher skills training), community (e.g., Juvenile justice system, church support systems), medical community (e.g., pediatrics, psychiatry)
- Multisystemic therapy was highly innovative for it's time, utilizing multiple targets of intervention, multiple systems, using an evidence-based research paradigm with high-risk populations (Youth in the Juvenile justice system).

FAMILY AND PARENT-CENTERED INTERVENTIONS-MST

- So what do we do when we have an innovative, evidence-based intervention that appears to work with high-risk populations? Adapt it to the pediatric world! Ellis and Naar king's work with Type 1 Diabetes
- Have utilized MST targeting families of adolescent youth with Poorly controlled Type 1 diabetes
- Home based services provided in delivering MST
- Have demonstrated improved glycemic control, greater adherence, fewer hospital admissions, and lower costs

FAMILY AND PARENT-CENTERED INTERVENTIONS- PRISM-P AND MARISSA HILLIARD'S WORK



- **MARISSA HILLIARD'S WORK**
- DR. HILLIARD IS DOING SOME EXCITING RESEARCH, WITH A FOCUS ON A **STRENGTH'S BASED APPROACH TO BUILDING RESILIENCE IN FAMILIES OF YOUTH WITH TYPE 1 DIABETES**
- FOCUS IS ALSO ON **THE SOCIAL DETERMINANTS OF HEALTH, INCLUDING INEQUITIES THAT EXIST AND HAVE BEEN WELL-DOCUMENTED IN MARGINALIZED PEOPLE**
- HOW DO WE CAPITALIZE ON EXISTING RESILIENCE? ALTHOUGH RISKS EXIST AT INDIVIDUAL, FAMILY, AND SYSTEMS LEVEL, RESILIENCE HAPPENS!

FAMILY AND PARENT-CENTERED INTERVENTIONS- PRISM-P AND MARISSA HILLIARD'S WORK

- Evaluate Strengths and Assets at the:
- **Individual level** (Cognitive abilities e.g., Self-efficacy ,Optimism, positive outlook, Humor, Talents, Faith/meaning)
- **Family level** (Close relationship with caring adult, Predictable home environment, Supportive family interactions, Prosocial peer group)
- **Systems Level** (High quality education. Public safety, Access to healthcare, Air quality, green space, Financial resources, Equity)

Family and Parent-Centered Interventions-Marissa Hilliard's Work

- 3 different interventions, including:
- 1. **"Type 1 Doing Well" M health App for parents of teens with T1D**
  Designed w/ input from teens with T1D, their parents, and pediatric diabetes care providers

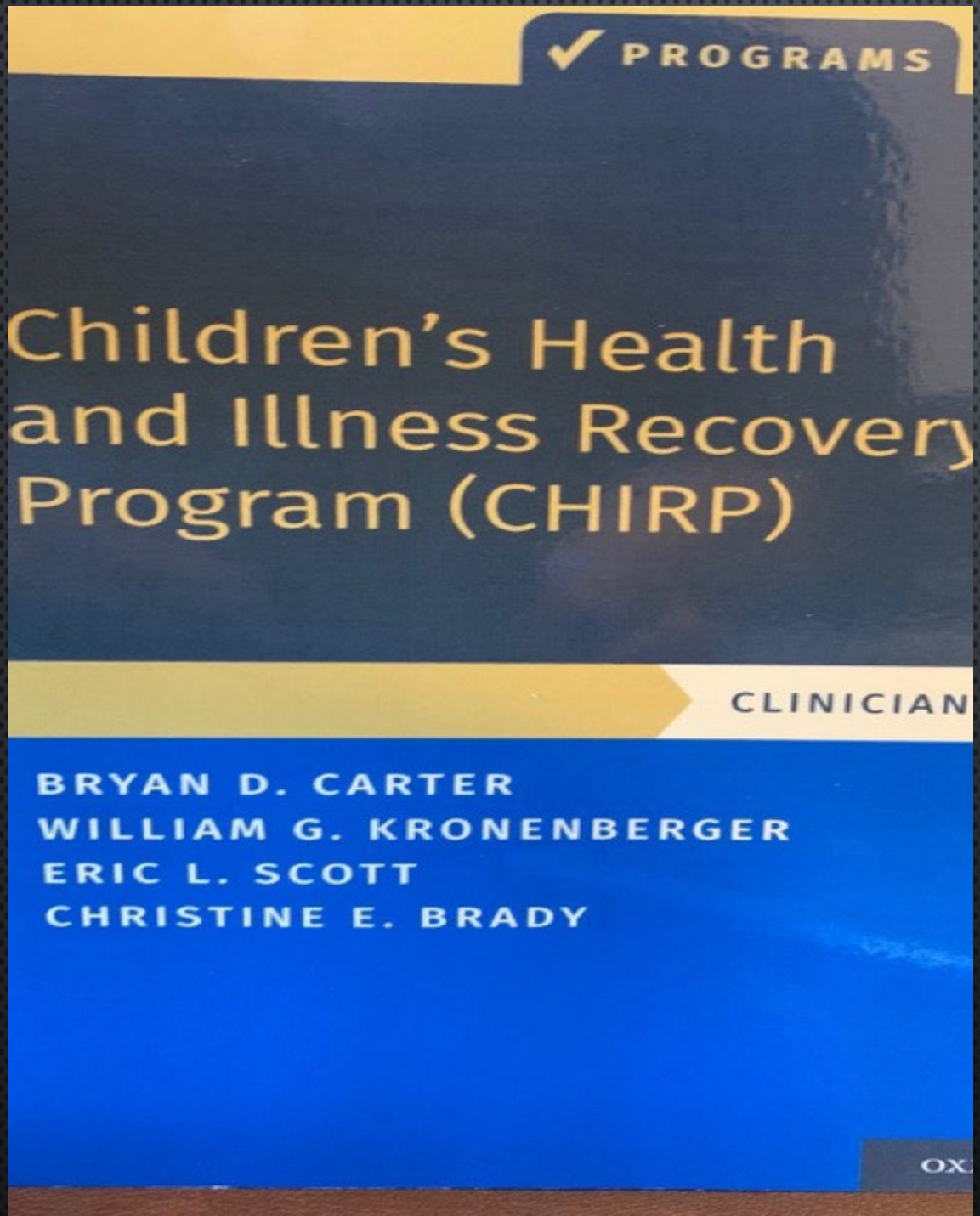
- Intervention Components
  - Parents taught to recognize and praise strengths
  - Parents record/report teen's positive diabetes-related behaviors (strengths)
  - Summarized teens top weekly strengths, encouraged praise

Family and Parent-Centered Interventions-Marissa Hilliard's Work

- 2. **Diabetes Strengths Study**
- Clinical encounters focused on reinforcing strengths
  - Delivered by diabetes care providers at 2 clinic visits
- Intervention components
  - Starts with a Review of the 'Diabetes Strengths Profile" of teen's T1D strengths
  - Make positive, reinforcing statements, elicit discussion about strengths & adherence behaviors
  - Preliminary results show changes in communication style, attitude towards visits, decrease in diabetes distress and family conflict

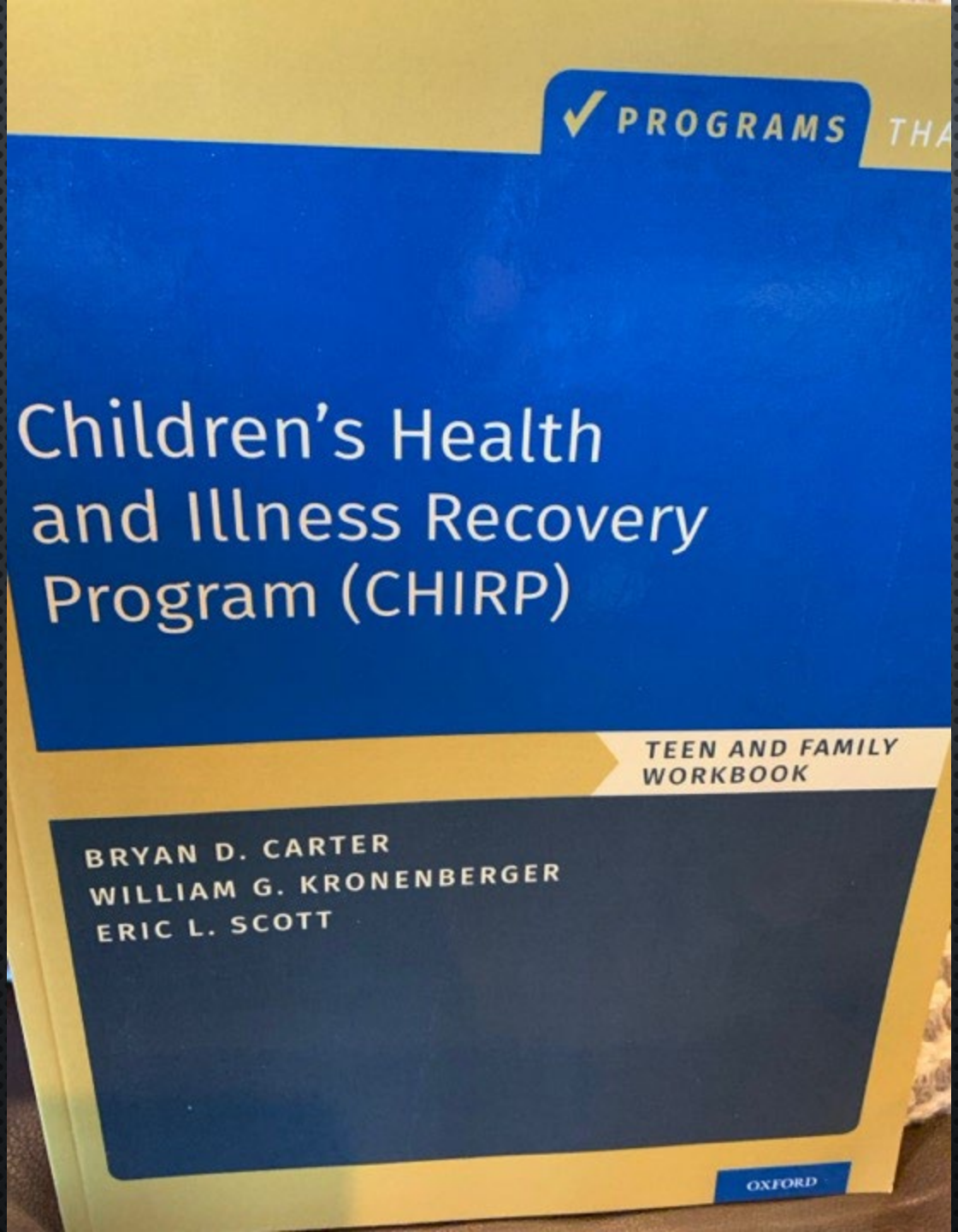
Family and Parent-Centered Interventions-Marissa Hilliard's Work

- **3. Dia-Better together Intervention**
- Is a Strengths-based, peer support intervention during transition from pediatric to adult care
  - Targets Young adults (17-25 y.o.) enrolled after final pediatric visit
- Intervention Components
  - Peer mentors provide strengths-based support & serve as role models, also providing accountability
  - Includes Goal setting and problem-solving approaches
  - Attempts to Enhance social support and diabetes-related communication
  - Also includes Stress management & coping skills



FAMILY AND PARENT-CENTERED INTERVENTIONS

- Carter, Kronenberger, & Scott (2020). The Children's Health and Illness Recovery Program



FAMILY AND PARENT-CENTERED INTERVENTIONS

- Carter, Kronenberger, & Scott (2020). The Children's Health and Illness Recovery Program

THE FOCUS OF CHIRP

- CHIRP IS AN INTERDISCIPLINARY FAMILY-BASED TREATMENT PROGRAM DESIGNED TO MAXIMIZE THE FUNCTIONING OF TEENS WITH A CHRONIC ILLNESS OR HEALTH CONDITION.
- DEVELOPED FROM EXISTING EVIDENCE-BASED LITERATURE FOR ADOLESCENTS WITH CHRONIC PHYSICAL ILLNESS
- HAS BOTH A CLINICIAN'S GUIDE AND A TEEN AND FAMILY HANDBOOK
- CLINICIAN'S GUIDE DESCRIBES THE PHILOSOPHY , PRAGMATICS AND ART OF WORKING WITH VARIOUS POPULATIONS, AS WELL AS THE TOOLS NEEDED TO PROVIDE A COLLABORATIVE INTERDISCIPLINARY TREATMENT TEAM
- BASED IN PART UPON THE TRANSACTIONAL STRESS AND COPING MODEL, THE FUNCTIONAL DISABILITY MODEL FOR PEDIATRIC CHRONIC ILLNESS AS WELL AS ELEMENTS OF BEHAVIORAL FAMILY SYSTEMS THERAPY

Elements of CHIRP Treatment Approach-Key Foundations

- Developing a chronic-treatable illness perspective (your health condition can be managed, but it may not be cured)
- Embracing a coping approach
- Moving from a state of functional disability to functioning.
- Resuming increased approximations to "normalcy"
- Adopting an organized program of graduated exercise and activity
- Family-based cognitive behavioral interventions
- Coordinated medical management of illness and symptoms
- Improved Sleep behavior
- Interdisciplinary collaboration, coordination, and communications
- Employing a developmental perspective

CHIRP SESSIONS

- 1. Stress identification and Management
- 2. Problem solving skills
- 3. Relaxation skills
- 4. Thought challenging and thought changing skills
- 5. time management and Prioritization
- 6. Increasing teen independence
- 7. Assertiveness and relationships
- 8. Family roles, communication and support
- 9. Keys to Maintaining progress
- 10. Skill reinforcement and relapse prevention

REMEMBER…

……

KEY PRINCIPLES OF FAMILY SYSTEMS, CAREGIVER-CENTERED APPROACHES

Develop a warm, genuine relationship with individuals, subsystems, and the family as a unit

"Strive to create a balanced therapeutic alliance with all members;

"Clarify each members commitment to change" and "Nurture a shared sense of purpose".

KEY PRINCIPLES

"Help family members imagine the personal and collective benefits by expressing optimism for the possibility of change"

"Adapt evidence-based interventions that respect client's cultural diversity, being mindful of cultural variables, socioeconomics, immigration status, racism, sexism, heterosexism as well as the role of culture to family dynamics (hierarchy, power, boundaries, extended family members. "

"Work with subsystems to prepare them to collaborate on difficult issues.

KEY PRINCIPLES

"Strengthen boundaries between people and subsystems"

"Strive to change family members experience of each other (e.g., attachment ruptures, problem solving skills, conflict management).

"Orchestrate the acquisition of needed resources for individuals struggling with serious mental health or substance abuse issues."

KEY PRINCIPALS

"Help family members consider alternate, more constructive attributions for each other's negative behaviors (and those of physicians, nurses, etc). **Emphasize the strengths and positive characteristics of other individuals and subsystems.**

"Directly address dysfunctional and destructive behavior"

"Respond sensitively and in a supported way to patients and families who feel blamed for their limitations".

CASE EXAMPLES-THE GOTEBO KID

- "The newly diagnosed kid from Gotebo, OK. Miguel is a 7-year-old male from rural Oklahoma. Following multiple workups at the regional medical center, referred to Childrens of OK and diagnosed with ALL.
- Mother is Currently not working, but previously was in Home health. Dad is a long- distance truck driver for a meat packing Plant. Long hours on the road. Two other younger sibs, one with severe asthma.

CASE EXAMPLES-THE GOTEBO KID

- MIGUEL IS EXPERIENCING SIGNIFICANT ANXIETY AND FEAR DURING THE INITIAL DAYS IN THE HOSPITAL. CLINGS TO MOM ALMOST CONSTANTLY.
- DAD IS PRESENT FOR THE FIRST FOUR DAYS AND THEN HAS TO RETURN TO WORK FOR A WEEK ON THE ROAD. THIS WILL BE THE PATTERN FOR HIM.
- YOUNGER SIBS ARE STAYING WITH MOM'S SISTER, WHO LIVES 2 BLOCKS AWAY FROM THEIR HOUSE.
- MOM IS LOOKING VERY OVERWHELMED.

CASE EXAMPLES

"The Case of the Gotebo Kid

What are their respective roles? Boundaries and alignments?

What is the function of his behavior?

What are their assets?

What are the risks?

Who are the "players" in the system, and how many systems do you involve?

Which Treatment Approache(s) do you adopt?

CASE EXAMPLES-THE GOTEBO KID

"What are their respective roles? Boundaries and alignments? Family appears to have good boundaries, strong communication, clear role relationships

What is the function of the behavior? Miguel has always been a somewhat shy, anxious child. Temperament plays a role. Overwhelmed by the newness of the situation. Concern that mother may reinforce this behavior over time

What are their assets and and strengths? Cohesive family, no significant history of serious mental health issues or dysfunction. Some (but not a lot) of social/community support currently.

What are the risks for the family? Underinsured, lots of bills coming in, Dad has to work leaving mom to assume the majority of caregiving roles, distance from OKC, Roles will be shifting

Who are the "players" in the system, and how many systems do you involve? Miguel, Mom and Dad, siblings, entire hospital team, mom's sister, the community in Gotebo

Which Treatment Approach(s) do you adopt and integrate?

CASE EXAMPLES-THE GOTEBO KID

Treatment Approaches-Following Psychosocial Risk Assessment using the PAT….

Mom-1) supportive psychotherapy. 2) parenting strategies, including how to help manage Miguels's anxiety, 3) uncertainty management, 4) problem solving therapy.

Miguel: 1) Coordinated efforts with Ped Psych And Child Life for anxiety management, self-soothing/ Relaxation training and 2) reward program

Dad:1) supportive therapy via phone contact, 2) uncertainty management, 3) problem-solving therapy

Sibs: 1) discussions with Mom and Dad assessing sibling adjustment, 2) how to talk with them about cancer, 3) assessing support systems in their home community, including support for sib with asthma

School: 1) established communication between our Center and school system to begin discussion of transition back to school, 2) provided them with resources on how to discuss with fellow students/teachers about Bradley's diagnosis and how to support hm.

Treatment Approaches

CASE EXAMPLES-THE GOTEBO KID

Community: 1) Discussed with mom various forms of community support and their availability/acceptability (e.g., church), 2) assessed local resources for short term counseling should they need it.

Hospital System: 1) Obviously, social service to help with major concerns about finances, lodging, travel costs, costs of daily living both in OKC and Gotebo

Cultural Considerations: 1) Understanding the culture of rurality in Northwestern Oklahoma, and more importantly that of the Mexican immigrants that came to OK to work in the meatpacking plants 25 years ago

CASE EXAMPLES-THE GOTEBO KID OUTCOMES

Mom-1) responded to supportive psychotherapy and was very open to parenting strategies, as it gave her a sense of control and mastery. Began to acquire uncertainty management skills. Problem solved how to manage accessing medical services in a rural area and communicate with her team.

Miguel: 1)Acquired a number of age-appropriate anxiety management skills, anxiety became much more manageable. 2)responded sell to reward system

Dad: 1) responded well to tele-health and began to Re-define the ways in which he could help his wife and Miguel above and beyond being the "breadwinner".

Sibs: 1) New support was garnered from the community in watching the sibs when mom and dad could not be present. 2) gained understanding of their brothers' treatment course in language they could understand

School: 1)availed themselves of psychoeducational programs and began to implement them with Miguel's fellow students as well as other staff.

Case Examples

- "The Case of the Bad a** Noncomplier
- 1. Lonnie Is a 17-year-old male. Shot Two years ago during an armed robbery with subsequent Paraplegia. He is estranged from his parents currently and couch surfs with friends in the years since he left inpatient rehab
- Longstanding History of Noncompliance with wheelchair exercises, and "well known" to the staff of the rehab center.
- Subsequent decubitus ulcers which have been surgically repaired
- **Currently re-Admitted to rehab center for infection**
- Surgeons do not want to do surgery again. Discussion of discharge from the system
- Consult request from physician-Is there anything left to try?

CASE EXAMPLES

"The Case of the Bad A** Noncomplier

What are their respective roles? Boundaries and alignments?

What is the function of his behavior?

What are their assets?

What are the risks?

Who are the "players" in the system, and how many systems do you involve?

Which Treatment Approache(s) do you adopt?

CASE EXAMPLES

- "The Case of the Bad Ass Noncomplier.
- **respective roles? Boundaries and alignments?** Schism is clearly emerging within the team and alliances developed. Ruptured relationship with Parents
- **What is the function of his behavior?** Depression and anger? Substance abuse? And what is going on with the team? Aren't they the caregivers?
- **What are His assets?** High level of contextual intelligence, street smart, and Tough. He is a Bad Ass.
- **What are His risks?** Lack of social and family support, Lack of life goals
- **Who are the Players in the system,** and how many systems do you involve? All members of the treatment team, Vocational Rehabilitation. **And what about his parents?**
- **Treatment Approaches?** MST + CHIRP + Traditional Psychotherapy

CASE EXAMPLES-BAD A**

"The Case of the Bad A** Noncomplier.

Goal number 1 is to bring the team together with a common goal-keep him in rehab, buy time to build support systems in the community and voc rehab. Set up a team meeting

Lonnie: Individual therapy. Motivational interviewing. Paradoxical intent. Behavioral intervention.

Family/Parents: Reach out to parents to try to repair damage in their relationship

Team Intervention-Keeping the entire team on board with providing support and encouragement

CASE EXAMPLES-THE BAD A** OUTCOMES

Lonnie: 1) responded to behavioral intervention, in part because he wanted to show the team he was smarter and more capable than them. Began to open up about depression and became more receptive to outpatient therapy and SCI support groups

Team: 1)Began to see Lonnie as more capable and less Self-destructive over time, Surgeons scheduled surgery for repair of his decubitus ulcers

Parents: 1) Slowly became more interested in repairing relationships with their son. Began to tell their story of believing they had "failed" their son.

Their "anger" turned to grief after multiple counseling sessions, and they were then willing to meet with him.

Cultural considerations: Working class. Individuals are defined by their physical status and work ethic. He was defined as "damaged goods".

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