Care Maps:
Ascending the Peaks, Navigating Valleys and Connecting Everything in Between
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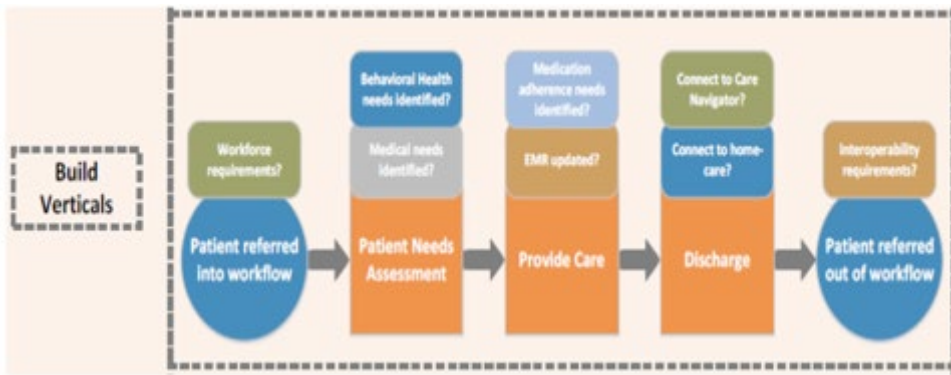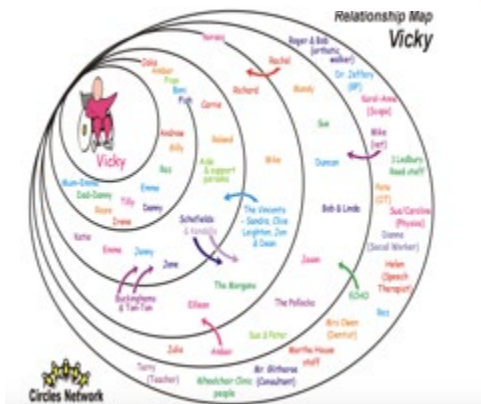
Conflicts of Interest

- None!

Objectives

- Explain the care mapping process and how it can improve communication, collaboration and care.
- Provide examples of how care maps can be used at the individual and systems levels.

Plans and Maps a Plenty in Disability and Healthcare: Person Centered Planning, Process Mapping and More
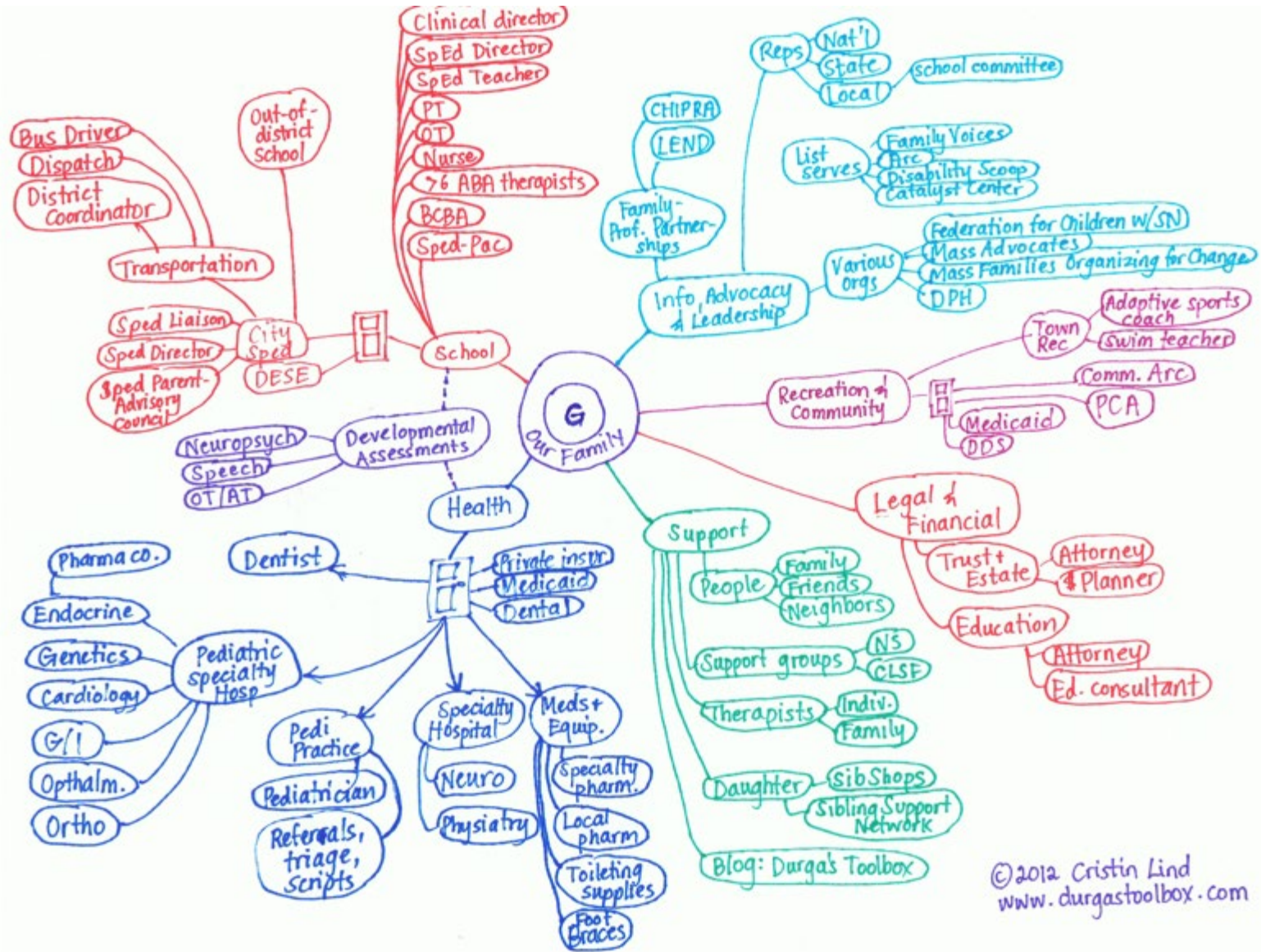

PATH (Planning Alternative Tomorrows with Hope)

"Each fresh peak ascended teaches something."
-Sir Martin Convay

The Original "Care Map"

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Neurological:
Agenesis Corpus Callosum
Cerebral Palsy
Cognitive Impairment
Cortical Vision Impairment

Otolaryngology:
Bi-lateral mild-moderate hearing loss
Recurrent Otitus Media

Pulmonary:
Laryngo malacia
Tracheal malacia
Chronic lung disease

Cardiac:
Mitral Valve Prolapse with Mitral regurgitation
Long Q-T syndrome
ASD and globular aortic root

Orthopedic:
Osteoporosis
Spasticity
Chronic Fractures
Calcaneous Feet
Bi-lateral patelar dislocation
Scoliosis

Gastrointestinal:
Intestinal dysmotility
Malnourishment
Bacterial Overgrowth syndrome
Short Gut Syndrome
Bishop-Koop Ostomy

Urinary:
Bi-lateral hydronephrosis
UPJ (Ureteropelvic junction) obstruction
Neurogenic bladder
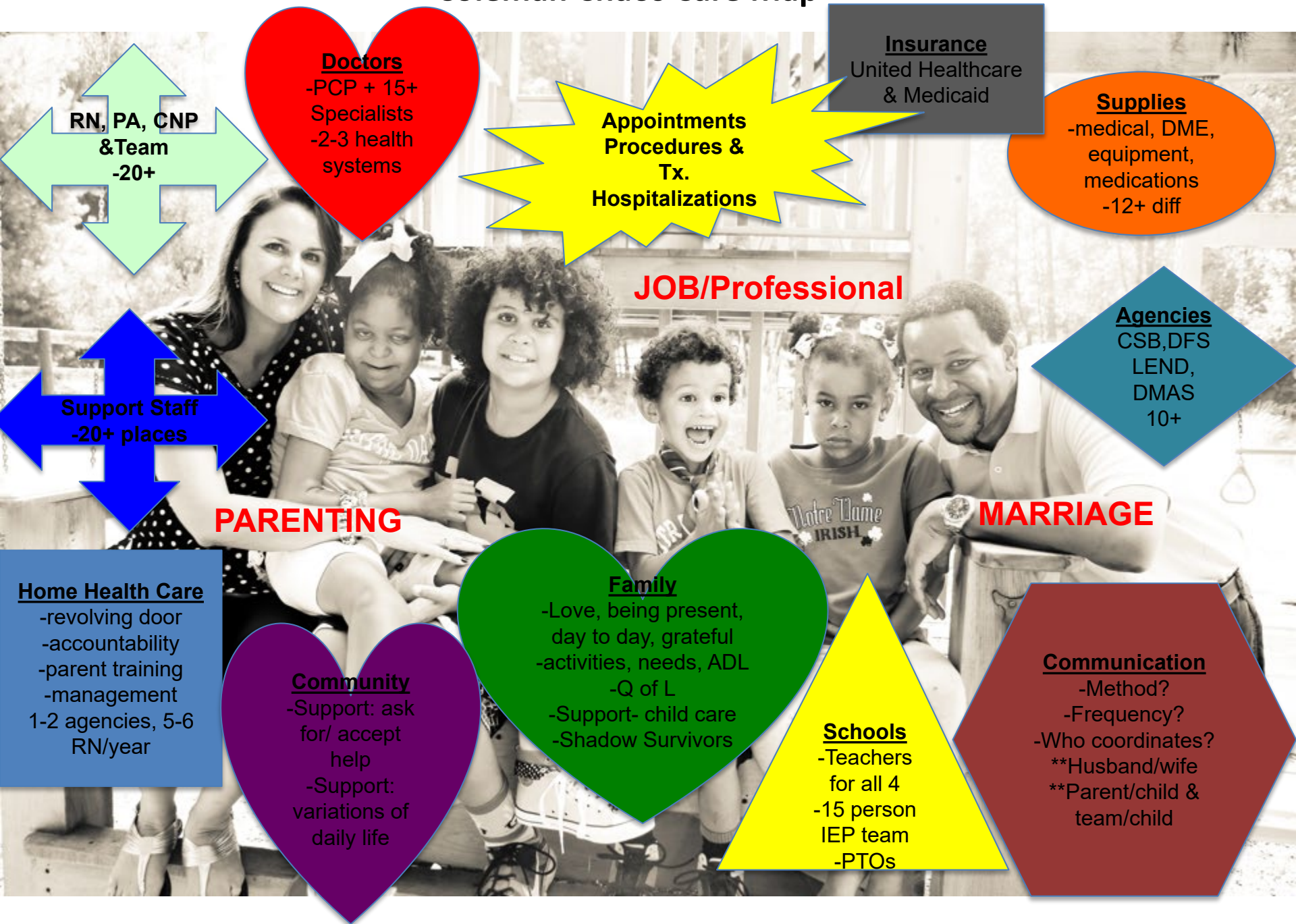Chronic Urinary Tract infections

Pain:
Chronic Pain
Neuropathy

The Coleman Chaos

16 physicians
20+ advanced care professionals
20+ support staff
3 health systems
Multiple Home Health Agencies
10 total local/state agencies
Commercial Insurance and Medicaid
12 + different suppliers
15 member IEP team
NO shared plan of care
EMRs do NOT communicate
"Team" does NOT communicate
NO true single locus of care/ PCMH
NO Care Coordinator (other than mom)
6 Coleman's

Coleman Chaos Care Map

RN, PA, CNP &Team -20+

Doctors
-PCP + 15+ Specialists
-2-3 health systems

Appointments Procedures & Tx. Hospitalizations

Insurance
United Healthcare & Medicaid

Supplies
-medical, DME, equipment, medications
-12+ diff

JOB/Professional

Agencies
CSB,DFS
LEND,
DMAS
10+

Support Staff -20+ places
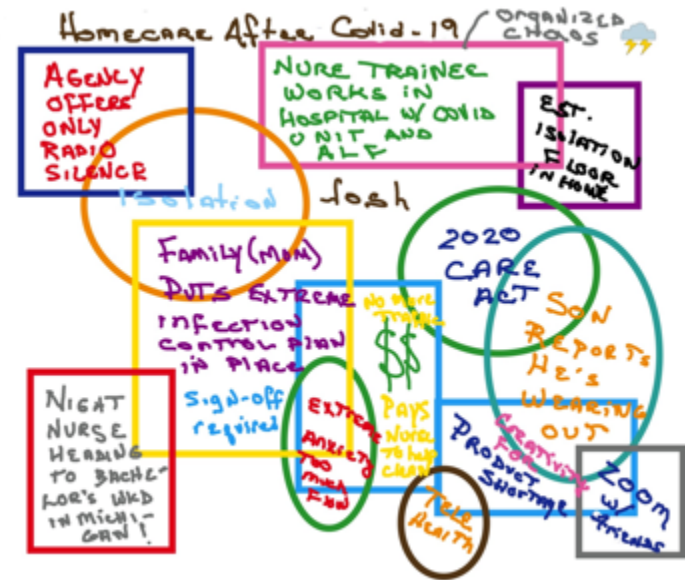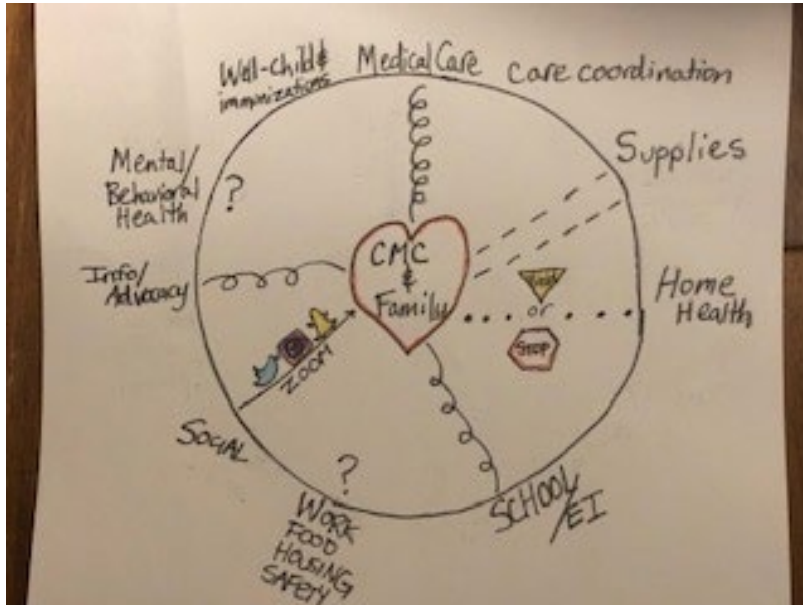
PARENTING

MARRIAGE

Home Health Care
-revolving door
-accountability
-parent training
-management
1-2 agencies, 5-6 RN/year

Community
-Support: ask for/ accept help
-Support: variations of daily life

Family
-Love, being present, day to day, grateful
-activities, needs, ADL
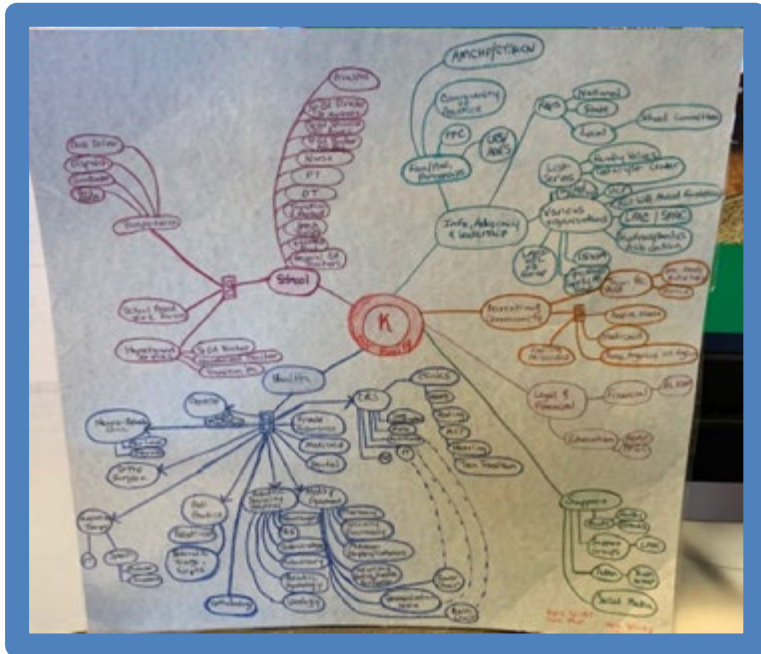-Q of L
-Support- child care
-Shadow Survivors

Schools
-Teachers for all 4
-15 person IEP team
-PTOs

Communication
-Method?
-Frequency?
-Who coordinates?
**Husband/wife
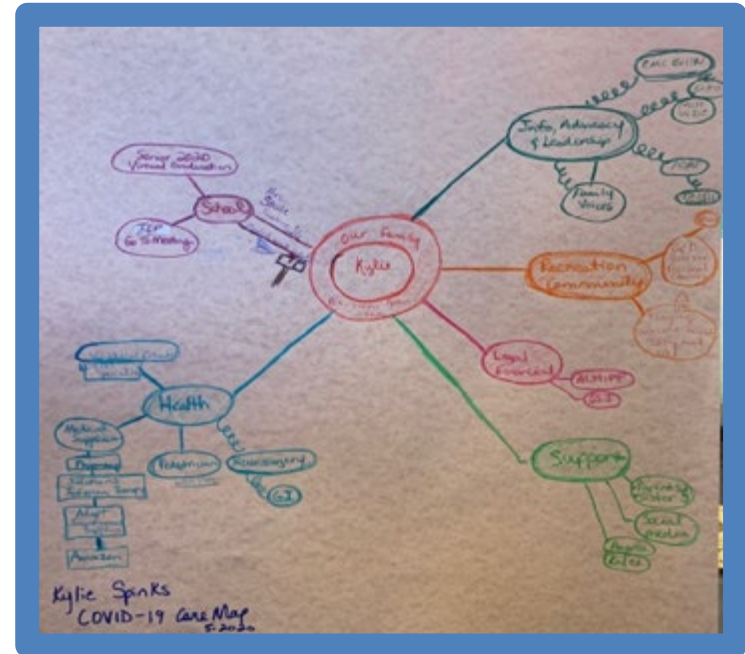**Parent/child & team/child

The Children with Medical Complexity Collaboration Innovation and Improvement Network (CoIIN):

Individual to Quality Improvement State Team to Network
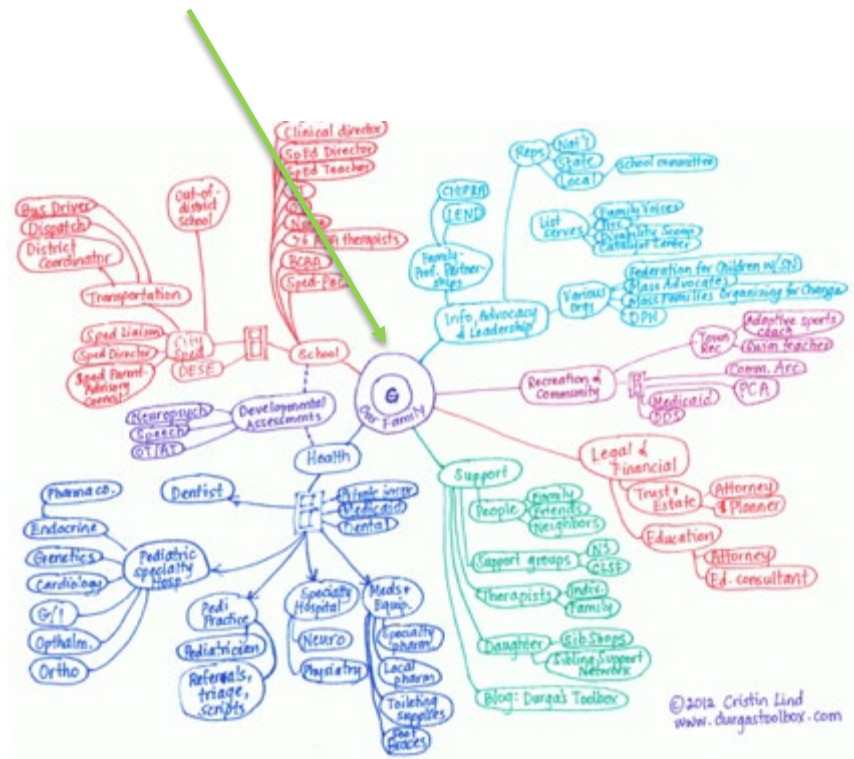
Care Maps: Our Lives are a PDSA Cycle

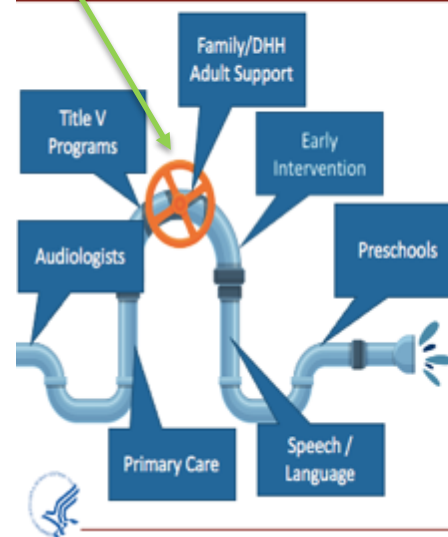**Smiley Kylie's Pre-COVID Care Map**

Smiley Kylie's COVID 19 Care Map

Systems Level: Map the Change to <u>Enact</u> the Blueprint for Change

"For too long, the system of services for CYSHCN and families has been **designed around the services themselves**. . . . *Reimagining* the system around the life course of the CYSHCN entails thinking about a **proactive**, **human-centered** system that addresses health through all of its determinants, and views access as a **journey built on relationships instead of a series of transactions**." (Access to Services, Kuo et al. 2022)

So, What is in a Care Map?
How Can We Use it for the Peaks, Valleys and Everything in Between?

- Make sense of the chaos
    - For family
    - For PCP and care team
- Communication tool
- QI tool
- Process/ systems change map

Resources

- Bost**on Children's Care map site-** includes important links to: Care Map Guide for Patients/ Families, Care Map Guide for Professionals, and information about Care Map App.

- **Family Voices of Wisconsin Care Notebook** publication has instructions, guide and templates to use in creating a care map. This article shares about **care map training session** with families.

- Complex Child Online Publication **article** about care mapping.

- **MCHB Blueprint for Change** and **Pediatrics Supplement on Blueprint for Change**

- Peer Reviewed Journal publications:
  - Developmental Medicine and child Neurology: **Care Maps for Children with Medical Complexity**
  - Pediatrics article, **Care Coordination for Children with Medical Complexity: Whose Care is it Anyway?,** uses care map for illustration, discussion and strategizing