



familyto**family**

Health Information Center

MARTIN BLAIR, PRINCIPAL INVESTIGATOR
JENNIFER BANNA, MT F2F HIC COORDINATOR
SHAWNA HANSON, MT F2F HIC OUTREACH COORDINATOR

THE BEST BEGINNINGS ADVISORY
COUNCIL (BBAC)

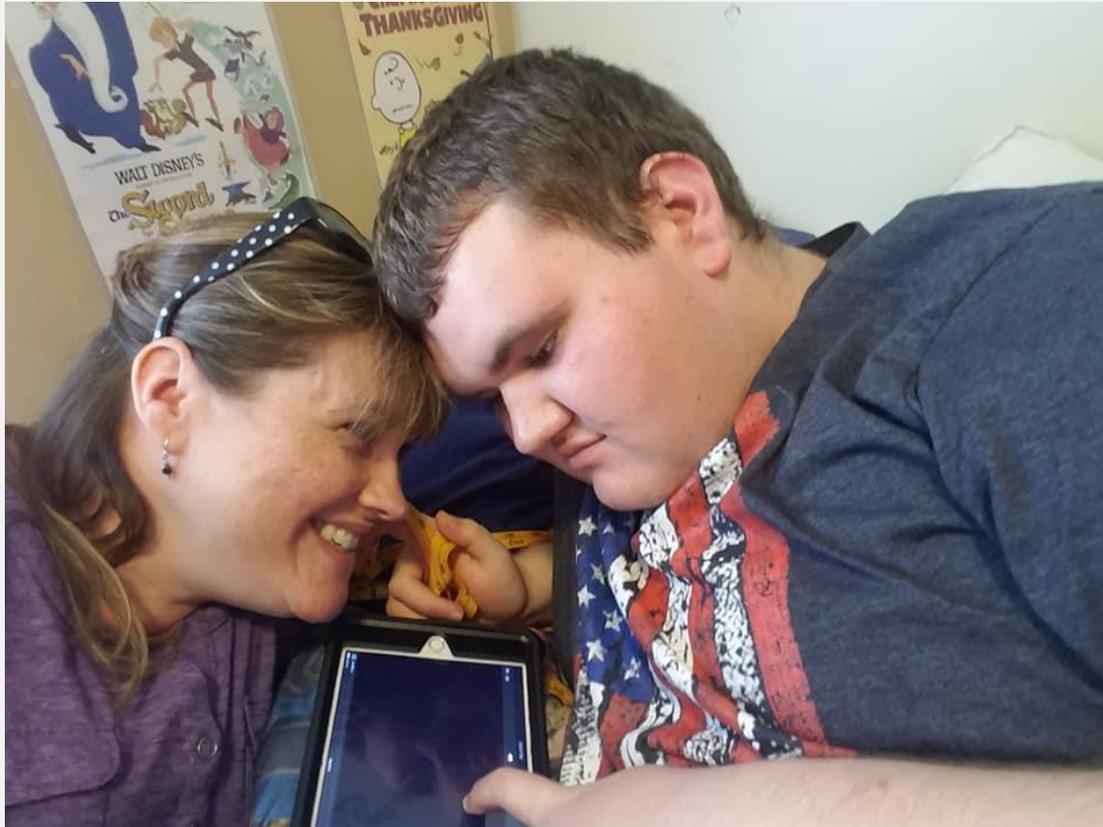
AND

THE MONTANA FAMILY TO FAMILY
HEALTH INFORMATION CENTER
(MT F2F HIC)

WHY IS THIS WORK IMPORTANT TO US?



SHAWNA HANSON, CENTER OUTREACH



- Severe autism, nonverbal, physically aggressive.
- At age 17, behaviors escalated.
- Family unsafe, bystanders unsafe.

WHEN WE CAME TO CRISIS,
THERE WAS NO BLUE PRINT
FOR HOW TO GET HELP.

THE FIGHT FOR OUT-OF-
HOME TREATMENT =
HEARTACHE AND, ULTIMATELY,
PLACEMENT OF A
NONVERBAL CHILD 2,000
MILES AWAY FOR 15 MONTHS





IRONICALLY,
THE FIGHT TO
GET YOUR
CHILD BACK
INTO THE
STATE IS
NEARLY AS
DIFFICULT AS
GETTING
OUT-OF-STATE
CARE



JENN BANNA, CENTER
COORDINATOR



- PittHopkins Syndrome – rare genetic neurological disorder. 500 cases worldwide
- Diagnosed at 12 by Shodair/Ambry
- Difficulty finding specialists, in-home care providers
- Insurance coverage and waiver, social security struggles.
- Early intervention from Part C, receiving a waiver and support from online groups have helped our journey.

WHAT IS AN F2F HEALTH INFORMATION CENTER?

- **FAMILY led**
 - Funded by the Health Resources and Services Administration (HRSA) through the Title V Maternal and Child Health Services Block Grant
- One in each state, territories and on some reservations

OUR F2F START DATE: JUNE 1ST, 2019



- Prior Grant Holder: Parents, Let's Unite for Kids (PLUK)
- PLUK continues to be Montana's Parent Training Center, helping families advocate for their children and navigate the education system
- There will be overlap, but helping families navigate the *healthcare* system will primarily be the work of the Montana F2F Health Information Center

OUR DEFINITION OF CYSHCN

“Children and youth who have, or are at increased risk for, chronic, physical, developmental, behavioral, or emotional conditions and who also require health and related services beyond that required by children generally.”

Source: McPherson M, Arango P, Fox H, et al. “A new definition of children with special health care needs.” Pediatrics, 1998; 102: 137 – 140.

OUR STATE LANDSCAPE

- 46,000 (20.1%) children aged 0-17 in Montana were reported as being a CYSHCN
- 4,000 children in foster care (CYSHCN)
- Grassroot efforts and individual voices are making change in communities all over the state
- Families are using social media to connect

WHAT DO WE MEAN BY 'HEALTHCARE SYSTEM'?

- **Private Insurance** – my child's claim was denied. Now what?
- **Waiver Program** – what does it pay for, how do I access it?
 - **Social Security Income** – what is the process?
 - **Specialty Care in Montana** – who provides it?
 - **Out-of-state Care** – how do I get it?
- **Transitions** – from hospital to home, out-of-state care to in-state care, child services to adult services
 - **Rural Therapy** – who are providers in my region?

WE INHERITED NO DATA – BUT ARE ACCESSING NEW
SOURCES OF DATA THROUGH THE GENEROSITY OF
OTHER PROJECTS

- Title V Needs Assessment
- MP2 Project (Montana Pediatrics Medical Passport)
- Center for Children, Families, and Workforce Development
- Rural Institute for Inclusive Communities
- Mountain States Regional Genetics Network
- Children's Special Health Services

AS A FAMILY-LED F2F, WE ARE MANDATED TO
SUPPORT FAMILIES WITH CYSHCN, AND TO
EDUCATE AGENCIES AND LEGISLATORS ABOUT
THEIR NEEDS.



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Health Information Center

OUR STATUTORY REQUIREMENTS

- Assist families in making informed choices about healthcare
- Provide information about available resources
- Support a model of collaboration between families and health professionals
- Conduct outreach and provide trainings as needs dictate
- Develop partnerships with organizations serving CYSHCN and their families

OUR INTERPRETATION OF THOSE MANDATES

- Introduce families to each other
- Connect families to programs *already in existence* in Montana
- Help families advocate for positive, systemic change
- Encourage CYSHCN to advocate for themselves
- Serve as an information hub and reliable resource for families and professionals, led by families intimately familiar with life in ‘the trenches’

THERE IS A LOT OF FREEDOM IN CHOOSING
WHAT SERVICES TO PROVIDE. EXAMPLES OF
WHAT OTHER STATES ARE DOING

Support Groups

Fact Sheets

Insurance Workshops

Care Notebooks

I:I Peer Support

Diagnosis-specific Trainings

Paperwork Assistance

Advocacy Workshops

Organized Efforts to Inform

Legislative Process



MAKING OUR PRESENCE KNOWN: FIRST STEPS

Meet with established providers and programs to better shape our F2F to Montana's needs, decreasing risk of redundant services

Personally interact with families, initially in Regions 2 and 5, to assess their expressed needs. [these are DDP (Developmental Disabilities Program) and CSPD (Comprehensive System of Personal Development)(OPI) regions]

Carefully construct and continually monitor a web site that will serve as a trusted, go-to guide to supports and resources.

Initiate an online, supportive community via Facebook

Parenting a child with
additional needs is like
playing a sport where
no one knows the rules,
the goal posts keep moving,
and there are more referees
than players!



OUR PLANS ARE BEING SHAPED INTO SOMETHING
DIFFERENT FROM OUR ORIGINAL IDEAS, INFORMED BY
SOLICITED FEEDBACK



WE LOOK TO
PARTNERS/STAKEHOLDERS
IN MONTANA, AND ASK:

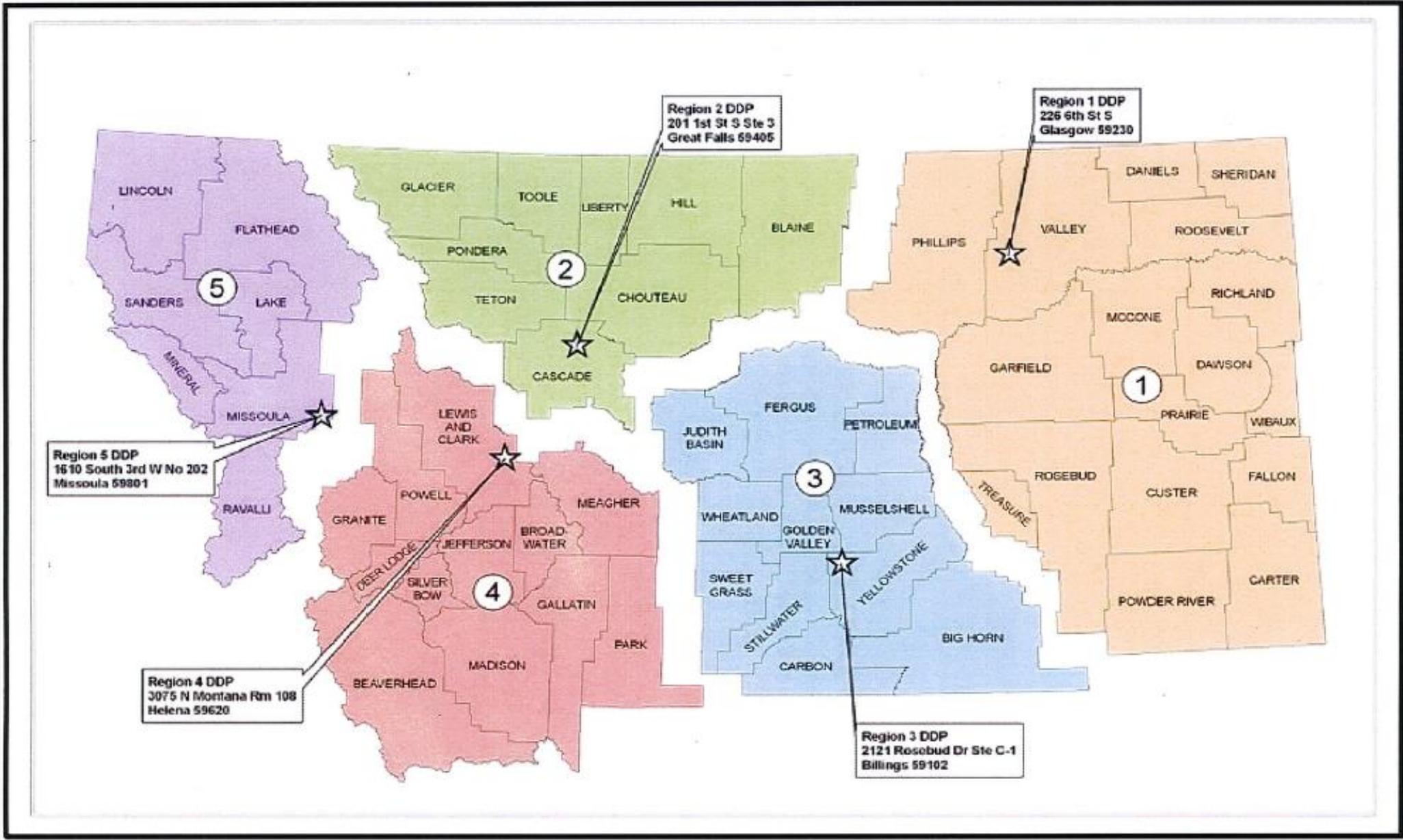
How can we leverage
our limited resources to
best serve families?

Where are the gaps and
how can we work
together to bridge
them?



FORMAL VS INFORMAL COMMUNITY SUPPORTS

- Formal supports are organizations or agencies that provide help or a service to the family. (Doctor offices, early intervention specialists, etc.)
- Informal supports include the support provided by a social network or community. (support groups, churches, etc.)



WE NEED YOUR HELP TO MAKE OUR F2F THE
RIGHT SUPPORT FOR MONTANA COMMUNITIES

- On the posted pages, please list the formal and informal supports in your communities.
- Are there barriers or gaps in your communities? A barrier is an obstacle that prevents access to health services. Try to be as specific as possible. A gap is something that is missing.

PLEASE BRAINSTORM AND IDENTIFY

- One informal support that you believe is unique to your region
- OR one barrier or gap in your region

IN CLOSING

- The Montana Family to Family Health Information Center is family led – it is for Montana families by Montana families who have navigated Montana systems.
- We feel that the success of families with CYSHCN depends on reliable, coordinated family centered resources. We want to partner with existing resources to:
 - Increase their capacity to work with these families and children
 - And discover gaps and work towards solutions to bridging them

THANK YOU FOR YOUR INPUT

WHERE WE ARE AND HOW TO CONTACT US

- *Email:* MontanaF2F@umontana.edu
- *Website (still under construction):*
f2f.ruralinstitute.umt.edu
- *Phone:* (406) 243-4570

Rural Institute
Inclusive Communities

