NAVIGATION AMONG THE MULTITUDES…
A 35 year old woman decides to have a baby...
Our first experience with ‘teaming’
The 20 week ultrasound...

- Kidney incongruence
- Heart issues
- Agenesis of the Corpus Callosum

- $1+1+1=$ Syndrome?
My OBGYN’s first comment,

“Well, this will be Interesting for you!”
Enter the first round of specialists or ‘Introduction to Care Coordination’

- Primary OBGYN
- Nephrologist
- Cardiologist
- Pediatric brain surgeon
- High risk OBGYN team

Consultations with all during pregnancy and all on-call for birth
What Worked / Didn’t Work

Worked

- Engaged, calm demeanor of my OBGYN
- Knowledgeable and empathetic primary nurse
- Guidance with what specialists to contact
- Follow through via conversations and appointments – caring and engaged, not sympathetic or apologetic
And a baby is born!

- Unremarkable delivery
- APGAR of 4, but came up to a 7
- Difficulty feeding kept us an extra day
With many unknowns, we head home for our first week as new parents

OR

‘The First Transition’
Week One

- Failure to latch
- Failure to wake to eat
- Incessant crying when awake
- Odd eye fluttering
- Vomiting
- Unusual diaper findings
What Worked / Didn’t Work

Worked
What Worked / Didn’t Work

Worked
What Worked / Didn’t Work

Didn’t Work
- Disconnect between pregnancy / delivery system and baby care system
- No relationship with Primary Care Pediatrician
- No baseline of what was ‘normal’ for the first week of parenthood
- Uncertain who to call or talk to about concerns
First ‘well baby?’ visit

- “She’s lost weight, Doctor” “Yeah, babies often do that in the first week”
- “Could the eye fluttering be seizures, Doctor?” “Maybe”
- “She seems to have strange looking poop, Doctor” “Hmmm...”
What Worked / Didn’t Work

Didn’t Work

- Not familiar with child
- No previous relationship
- Didn’t ask us many questions or build relationship
- Lack of engagement that felt like lack of caring
- No follow up
On call Doc. Different clinic.

Come in tomorrow morning first thing and I’ll see you.

3 hours later, one week to the minute of her delivery, Neva was being rolled into surgery to discover Hirschprung’s Disease.
What Worked / Didn’t Work

Worked

- Immediate response
- Pediatrician looked us in the eye and probed our abilities, understandings and needs
- Referred us to specialists without delay
- Followed through by visiting at the hospital / calls
- Has ALWAYS looked to us for our input and expertise
- We felt cared for
We’re in the hospital, might as well do our follow ups…

- Team Neva
  - Pediatrician
  - Developmental Behavioral Pediatrician
  - Pediatric Gastrointestinal Surgeon
  - Cardiologist
  - Neurologist
  - Geneticist
  - Nephrologist
  - Feeding specialist
  - Respiratory specialists
  - Rotating Nursing staff
  - Residents
  - Phlebotomists
  - X-ray technicians
Our baby is One Week Old
(and we are 1-week post-partum with our first child...)

☐ Everyone is talking to us, but are you talking to each other?
☐ Can we all sit down and talk together?
☐ What is the plan?
☐ What is our role?
☐ What is going on?
☐ How do we get our questions addressed?
☐ Are we looking at my child as a whole or a collection of parts?
After that first week

- Many follow up doctor and specialist appointments
- More surgeries and hospital stays
- Insurance coordination
- Therapies
- Consultations
- Equipment
What Worked / Didn’t Work

Worked - family

- Our ability to understand and process
- Our believe in our abilities and role as parents and ‘new experts’
- Our flexibility and proximity to the hospital / specialists
- Our language proficiency
- Our patience and persistence
- Good medical insurance
- Sense of humor
- Passible mental health and strong communication abilities
What Worked / Didn’t Work

Worked – Medical

- Everyone incredibly caring
- We felt our input and knowledge was respected and valued
- All of the scheduling and reception staff were very patient with us and familiar with our child
- Our insurance appointed a coordinator to help us with insurance billings and management
What Worked / Didn’t Work

Didn’t Work

- An unbelievable number of Doctors, Specialists, Residents, Therapists and bills to manage and coordinate
- Had to repeat, repeat, repeat to each new specialist that came into the room
- Felt very alone
- No sleep / No respite
- Uncertain of any support available
- Uncertain of ‘next steps’
Impact on our lives

- I left a creatively challenging and decent paying career to coordinate our daughter’s supports
- My husband took on a 2nd job and developed flexible work hours
- We became ‘experts’ in areas that we never dreamed of becoming (or ever wanted)
- We wouldn’t dream of taking career risks that leave us without insurance
- We wouldn’t consider relocating to an area that didn’t have experts in our needed support fields
- On our own we developed a strong system of parent supports
In a Perfect World

- Coordinated Care Person
- Doctors and parents sit down to discuss patient together
- How many times do I have to fill out the same paperwork?
- Parent to Parent contact – natural supports
- Community supports?
- Extended follow up through childhood
- You don’t know what you don’t know…
Team Neva Year 10 or ‘The Care Coordination Continues’

- Pediatrician
- Podiatrist
- Ophthalmologist
- Gastrointestinologist
- Nutritionist
- Teachers
- Tutors
- Educational assistants
- Occupational therapists
- Physical therapists
- Speech Language therapists
- Vision therapists
- Feeding specialists
- Camp councilors and assistants
We took a trip to Italy

- How to summarize and strategize everyday care needs and minor emergencies (the Neva 101 document)
- Major emergencies
- But, what if we didn’t come back?
Family

like branches on a tree,
we all grow in different
directions yet our roots remain as one

My Family
How we got from then to now:

- Caring for the child means including their family in the bigger picture
- The things that made a difference
- Our hardest year
Parents As Partners

- What is the first step to building open communication?
- Keeping it ongoing
- Building family capacity
The First Step

- Active and sincere listening
- Building Trust
- Building Relationship
How did Dr. Temple gain our trust & confidence?

- Upon entering the room Gabriel gets his first attention
- He plays with him
- He takes the time to really listen to our concerns and view point with respect
Talking about the hard stuff

- Length of relationship and trust helps here
- Keeping it strength based
- Not any one family can hang out a sign stating “Perfect Family Lives Here”
The first steps are the hardest

Gabriel’s first Christmas 😊
Building Family Capacity

- Working with the family as a partner vs. doing it for them
- Building Peer Support and Community
- Education
Friends For Life
Get Them Hooked In

- Oregon Family To Family Health and Information Center
  www.oregonfamilytofamily.org

- Community Connections Network
  www.occysnhn.org

- The Swindells Child Disability Resource Center
  www.providence.org/childcenter

- Oregon Family Support Network
  www.ofsn.org
What This Means

- Earlier interventions
- Stronger families
- More inclusive opportunities
- KUDDOS to everyone of you

• My 15 year old daughter Kimberly with Gabriel, now four and a half years old