

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
- $1+1+1 = \text{Syndrome?}$

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

Green

- 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...

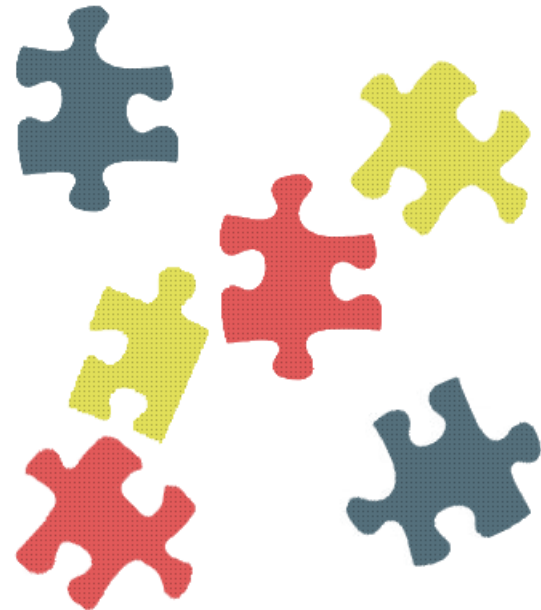
- Team Neva
 - Pediatrician
 - Developmental Behavioral Pediatrician
 - Pediatric Gastrointestinal Surgeon
 - Cardiologist
 - Neurologist
 - Geneticist
 - Nephrologist
 - Feeding specialist
 - Respiratory specialists
 - Rotating Nursing staff
 - Residents
 - Phlebotomists
 - X-ray technicians



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
- ❑ Gastroenterologist
- ❑ 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











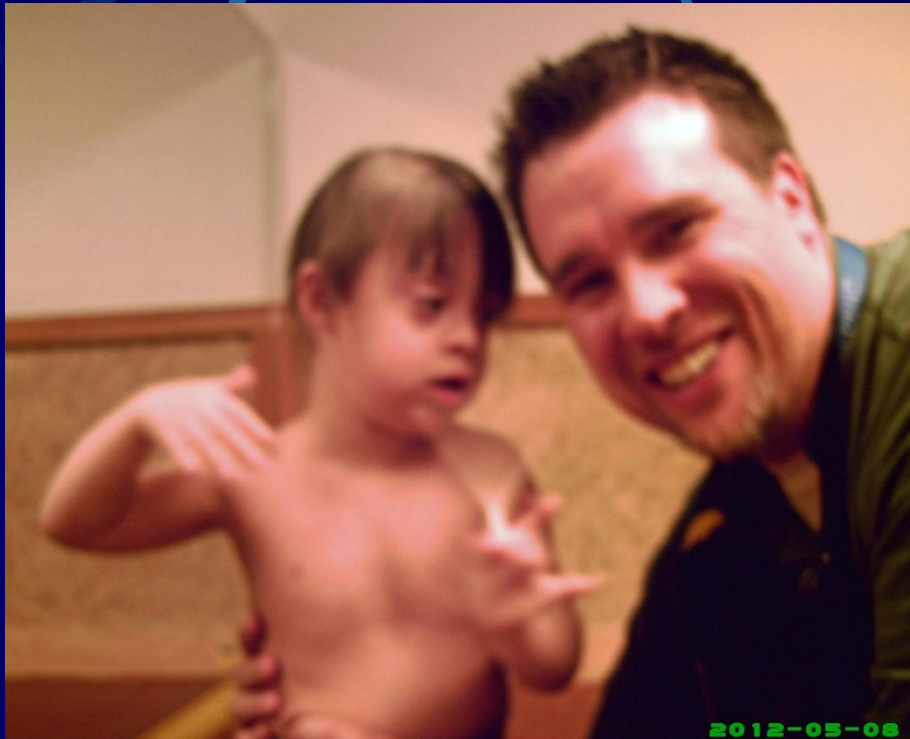
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The First Step

- Active and sincere listening
- Building Trust
- Building Relationship

THE FIRST STEP

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 ☺

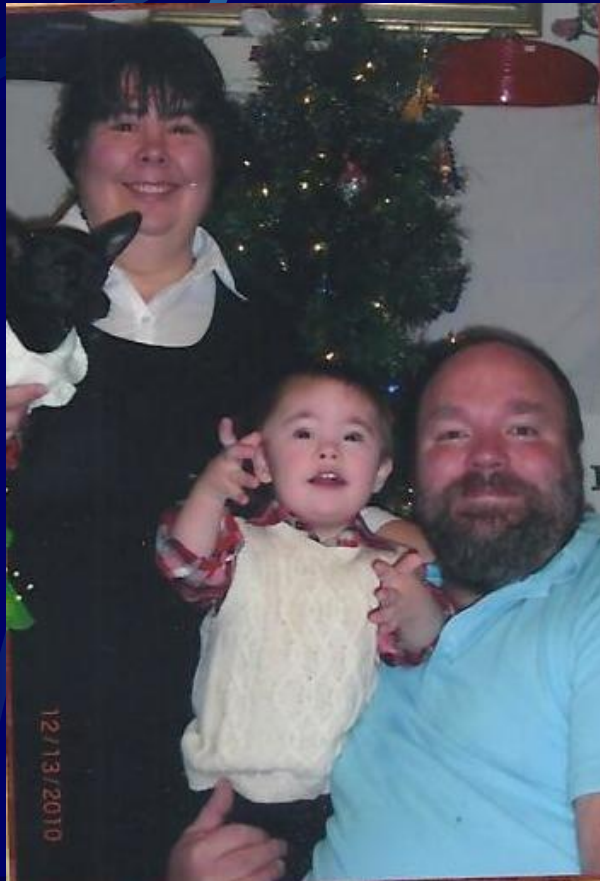


Building Family Capacity

- 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

- o Oregon Family To Family Health and Information Center
www.oregonfamilytofamily.org
- o Community Connections Network
www.occyshn.org
- o The Swindells Child Disability Resource Center
www.providence.org/childcenter
- o Oregon Family Support Network
www.ofsn.org

What This Means



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

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