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*Please note- the following outline reflects the many areas which I anticipated might be of interest to the participants. Due to the intentional free flowing nature of the event, not all subjects will be covered in my presentation or even in the discussion. The comments and tools are based on my personal experience and practice and are not intended to represent NICHQ doctrine.*

Subspecialists- we **like** to study the diseases and **love** to care for the patients!

### **What are we sharing?**

- Care of the child
  - As a whole person
  - In the context of family and community
  - In the framework of their whole life
- Management of the disease process
  - Knowledge of the disease/ disorder
  - Experience with the disease/ disorder
  - Tools to manage disease/ disorder

### **How can we share nicely?**

- Medical home as a philosophy of care with a neighborhood of care givers
  - All the pros and cons of a committee or collaborative
  - Sometimes there needs to be one person in charge, but
  - Does it have to be the same person in every situation?
- Do all the stakeholders have a say in everything?
  - primary providers
  - specialists
  - community based organizations including school
  - families

### **My mother told me not to generalize- (please don't tell her about these next comments).**

My experiences when the disease process is complex and/or rare:

#### Hospital multidisciplinary setting

- The clinic team is in charge as group.
- Specific responsibilities are fluid and often based on consensus and habit.
- There is often a team member (social worker or nurse) who has the strongest grasp on social support and community based resources.
- Communication happens without too much insistence or assistance from the family.

#### Urban setting

- The specialists are in charge of the disease processes and

Many primary care providers hand off care of the child as well...

- A specialist taking ownership of the patient seems to follow provider personality rather than which disease is most active.
- The specialist owner often directs communication among specialists but not always with the primary care provider.
- If one specialist does not assign themselves ownership of the patient then communication breaks down unless the family takes over.

#### Rural setting

- The primary care provider maintains ownership of the child and takes on much of the disease management as well.
- The specialists provide a detailed care plan with options, assistance as needed to the provider, and tools/ education to the primary care provider.
- The communication is often intrinsic when the specialist travels to a specialty clinic in a rural setting.
- The primary doctor usually is insistent on obtaining communication when patients travel to the specialists.

#### **Using a care plan for communication**

- Pros
  - Ideally assigns
    - Responsible party
    - Time line
    - Desired outcome
    - What to do if things don't go according to plan
  - Cons
    - They take a lot of time
    - How can you keep everyone's copy up to date?
    - Electronic medical records don't lend themselves to using them

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#### **What I'm using right now:**

The truth of the matter is that my current care plan was devised with the goal of communication with all stake holders in mind, but it actually is the most helpful to me in

understanding what is going on the patient’s life both where I am in charge and where I am not. I use these for my patients with more complex disorders and update them at each visit. It is helpful because I can just run through each item and receive an update from the family. It also reminds me to touch on aspects important to general care and medical home which might otherwise be forgotten.

The primary care providers seem to appreciate them, (That is if I ask. They have not filled my voice mail with enthusiastic messages.) but have not adopted them as a way of trading information back and forth, as I had hoped. Specifically I have received feedback that some primary providers would like to use them but it is difficult to do so in the electronic medical record. Families also comment that they like them at the visits, but it’s not clear that they use them as the portable communication tool I had envisioned.

Blank tool:

<b>Patient Name</b> <b>Date:</b>
<b>Problem:</b> <b>Discussion and Plan:</b> <b>Next step:</b>
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<b>Problem:</b> <b>Discussion and Plan:</b> <b>Next step:</b>
Emergency Plan
School/Daycare
Equipment
Dental and continence
Advanced directive
Social support
Transition to Adulthood
Follow up

Example plan:

Please note that **Next Step** is most helpful if it includes:

1. Who is the ‘owner’ of the process- meaning they make sure it gets done even if they don’t do all the work
2. A time line of what to expect and/or what to do
3. How to proceed if the plan breaks down or common predictable problems arise

<b>Patient Name</b> <b>Date:</b>
<p><b>Problem:</b> suspected seizures</p> <p><b>Discussion and Plan:</b> 3 episodes of arching and stiffening after feeding which last 30 seconds and do not stop with repositioning- most suggestive of seizures. pH probe was negative- GI doubts reflux.</p> <p><b>Next step: 1.</b> order for EEG placed at visit. Patient family should expect scheduling call in next 2 days. If not- call # to schedule. Family may call same # if they have not received results from Dr. Green 2 days after the study is completed.</p>
<p><b>Problem:</b> initiated seizure medication at this visit</p> <p><b>Discussion and Plan:</b></p> <p>Week #1: ½ tablet twice a day</p> <p>Week #2: 1 tablet twice a day</p> <p><b>Next step:</b> Week #3: continue 1 tablet twice a day and call with update to neurology office #.</p> <p>We reviewed side effects and medication literature was provided.</p> <p>We reviewed seizure safety and a handout was provided. All caregivers should know basic seizure safety/CPR.</p> <p>Suggest contact Epilepsy Foundation of America- flyer provided. Family encouraged to visit our family learning center as well.</p> <p>If rash develops take to PCP or urgent care. Stop medication until PCP OKs restarting. PCP may call Dr. Green or on-call doctor at # as needed.</p> <p>A prescription for Diastat was provided for events which last longer than 3 minutes.</p>
<p><b>Problem:</b> premature birth</p> <p><b>Discussion and Plan:</b> complicated by intraventricular hemorrhage</p> <p><b>Next step:</b> release form completed at last visit and faxed to prior PCP. Family to call that office to see if records have been sent. If records have been sent, family to alert Dr. Green's office. If not, they will direct prior PCP to fax records to #.</p>
<p><b>Problem:</b> orthotics no longer fitting</p> <p><b>Discussion and Plan:</b> patient last seen by rehab medicine in 2007</p> <p><b>Next step:</b> family to arrange follow up appointment by calling #</p>
<p><b>Problem:</b> missed appointment for flu shot due to cold</p> <p><b>Discussion and Plan:</b> now well</p> <p><b>Next step:</b> PCP manages immunizations</p>
<p>Emergency Plan: Seizure action plan completed at this visit. Family to give to school nurse and all care givers.</p>
<p>School/Daycare: in self-contained class room in public school</p>
<p>Equipment: wheelchair. Managed through vendor at school.</p>
<p>Orthotics- family to update with rehab medicine</p>
<p>Dental and continence: patient has regular dental care. Family reminded that Medicaid will cover diapers starting at 4 year old birthday. They should remind PCP or Dr. Green to provide a prescription at that time.</p>
<p>Advanced directive: full support</p>
<p>Social support: family would like to meet other families with seizures. Directed to Epilepsy Foundation and Family Voices for family to family support.</p>
<p>Transition to Adulthood: not applicable today</p>
<p>Follow up- in 2 months. Scheduling #</p>