Goal Setting with families of children who are medically complex
Going beyond levels of severity and delay
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Problems with “developmental delay”
• Atypicality
• Regression
• Stagnation
• Conditions that prevent development
• What happens when the child isn’t at a newborn level?

Does a medical diagnosis help?
• Precision of diagnosis
• Accuracy of diagnosis
• Variability of severity and prognosis within diagnosis
What about homeostasis?
- Can’t build strength without adequate respiration
- Can’t build strength without adequate cardiovascular function
- Can’t build attention periods of alertness
- Pain is debilitating
- Anxiety is debilitating

What about physiology?
- Does the reason for the impairment matter?
- Vision
- Site of motor abnormality
- Regression/dementia

Whose goals are they anyway?
- Parent
- Therapist
- Infant
Who is the recipient of services?

- Infant
- Parents
- Siblings
- Wider family

Goals for Anita

- What is Anita’s level of delay?
  - This is the picture of atypicality of physiology, homeostasis, and therefore development
  - Do the words matter?
  - Is there any age of infant for whom her behaviors would be normal?
  - Is there such a thing as “prenatal” level of development?

What is the basic goal for Anita?

- Life safety
  She is dependent on others to maintain her airway
  She cannot communicate hunger and requires skilled artificial feeding
  She cannot reliably communicate distress
  As far as we can tell from imaging and neurophysiologic information we don’t anticipate change in these problems
Can we be sure?

• No but if she improves we take it!
• Physiologic stability comes first
• No data set or published series can completely prognosticate for any one person

What about goals for Scottie?

• Scottie cannot control knee movement.
• Goal 1: Maintain knee range of motion from 90 to 180 degrees to allow sitting and standing
• Parents understand and practice ROM to BLE
• Parents understand s/s of injury and fracture to insensate skin
• Parents understand use of splinting to maintain ROM

More about Scottie

• Goal 2: Scottie needs adequate trunk strength to attain and maintain sitting
• Parents understand positioning program in prone and active exercise program to encourage strength in extensors and obliques
And more

- Scottie needs adequate UE strength to lift his weight for pressure relief and for ambulation with crutches or walker
- Parents understand play techniques to encourage UE weight bearing, range of motion, and strength eg ball play, resistance toys
- Scottie can be mobile in a room and misbehave

But whose goals are they?

- Do parents ask about these things?
- Do they need to know even if they don’t want to know?
- How much anticipatory guidance is appropriate for EI? How much should come at the parents’ lead? How much from the medical team?

And more

- Scottie needs awareness of others who ambulate with assistive devices
- Parents are given resources for meeting other families eg SBAA
- Parents are encouraged to bring Scottie to events like wheelchair basketball and track and field to help him and them see competent adults with disabilities
And more

- Scottie’s parents need to learn to respond to unwanted attention and advice from
  - Family members
  - Strangers
  - Friends
  - Scottie eventually needs to learn to explain his disability and to cope with these things too.

Damian

- Parent goal: return to oral feeding
- Parent goal: less stiffness
- Parent goal: focus

- What are the barriers to these goals?

What does the literature say?

- Symptomatic West syndrome usually predicts very severe impairment and ongoing epilepsy
- Does the use of the term “cerebral palsy” inform or confuse the parents?
- Is this term accurate?
- Does the MRI help us to explain?
What about the seizures?

• Seizure control is a medical goal, not a therapeutic one
• In this case it was not achieved
• What happens to alertness/consciousness during a seizure?

Is this really static?

• Cerebral palsy definitionally is a static encephalopathy BUT
• Epileptic encephalopathy is not static
• Limited treatment options for this child

So what about goals

• Parent education in handling for comfort, care, positioning
• Equipment to manage positioning and care
• Assessment for level of alertness
• Family education for prognosis and techniques of care
Michelle—an infant with a C5 quadriplegia and a traumatic brain injury

- Is she delayed? Is inability to roll over a sign of delay?
- What are appropriate motor goals for her?
- What are the effects of her sensory abnormalities?
- How do we teach her to play and move?

What kind of equipment?

- Something to hold her trunk and head upright
  - For stability of gaze and focus
  - For attention
  - For respiratory support and GI support

When motor and cognitive development are divergent

- Bring the world to the child
- Use equipment to allow for postural stability
- Use equipment for manipulation
- Use equipment for communication
- Use equipment for physiologic support
Positioning

- Gravity eliminated positioning for active movement
- Gravity eliminated positioning to avoid compression/contractures
- Positioning for best hand function

Mobility

- Clearly will need power
  - Begin to use switches for cause/effect
  - Movement experience so she can tolerate movement in space
  - Sitting equipment so she can face her parents
  - Needs mobility to learn to misbehave

What about the head injury?

- Slowdown in head growth a big concern
- Can’t precisely predict
- Want to avoid experiential deprivation
- Children with severe motor impairment often present as exceptionally intelligent
And those vital signs? What about health?

- Automatic dysreflexia can be life-threatening though not usually in infants
- Very poorly recognized
- Respiratory status of young children with C5 quadriplegia is very different than teens/young adults and adds to developmental and physiologic morbidity

So more goals

- Parents need to know respiratory management
- Parents need bowel and bladder management training
- Parents need skin and temperature management training

And adjustment

- Viewing the wheelchair positively
- Working on having Michelle direct her care and experience
- Parental education about future medical issues eg scoliosis, respiratory issues
Physiology Matters

• The more homeostatically stable the child is, the more energy will be available for emotion, learning, and attachment
• Some physiological barriers are insurmountable
• When development can’t be improved, ease of caretaking and future planning continue to be important