T 888.648.6228 E info@mitoaction.org PO Box 51474 Boston MA 02205 www.mitoaction.org

mito ACTION

Suggestions for Functional IFSP Goals and Strategies for Children with Mitochondrial Disease

"You can't change the wind, but you can choose how you set your sails." J. Dean

Family adjustment to diagnosis

- Emotional, social, spiritual support for parents and extended family: Mito can be a very isolating disease. Caring for a medically complex child is a 24 hour/day, 7 days/week commitment. Parents with chronically ill children have a unique perspective regarding the severity of any illnesses; a child with Mito whose medical involvement might be considered "mild" under these circumstances is often considered "moderately severe" by parents of healthy, typically developing children.
- Explaining Mito to siblings, friends, classmates, and extended family: Mitochondrial disease is frequently an "invisible illness." It can be difficult for people to understand a complex metabolic condition, realize that many seriously ill individuals may not "look sick," and that the child's ability to perform certain tasks may vary.
- Changes in family roles: Children with Mito and other metabolic diseases require much more care than many other children with disabilities and special health care needs. A parent may need to transition from being the breadwinner to becoming the caregiver. The parent's spouse/partner often needs to assume responsibilities that the caregiver used to manage. The balance of home and work duties becomes skewed, and the spouse/partner's list of responsibilities can grow to enormous proportions. Siblings may exhibit behavioral signs in response to emotions or as a quest for attention.
- Continuity of care when a child has frequent and/or long hospitalizations: Children with Mito and other metabolic disorders are often hospitalized frequently. Obviously, this can have a profound impact on the child's ability to continue making developmental progress. Often, simply maintaining current skills while hospitalized is an appropriate goal. However, remember that children with Mito are much more sensitive to alterations in homeostasis than their peers, and post-illness regression is very common. These regressions and skill variability do not simply reflect the efforts the parent, clinician, and child have made toward achieving their goals. They are related to mitochondrial disease itself.
- Prioritizing goals: What are the two or three most important goals in the child's IFSP? Which goals are most important to the parents and why?
- Communication: HIPAA regulations restrict communication between EI clinicians and hospital clinicians (PT, OT, SLP, Child Life specialists). In order to lower or eliminate communication barriers, consider creating the following:
    - Universal waiver for the EI clinician to provide a "traveling IFSP" for the child to use in other situations
    - Emphasis on the child rather than the illness
    - Care teams: EI's role in "the big picture"

- Poster with suggested activities

Encouraging growth and development when the child experiences profound fluctuations in energy and symptoms

- Pathophysiology of fatigue and alterations in energy production and storage
- Assessment and journal suggestions
- Documenting the "uh-oh scale" (What physical signs/symptoms mean everything is OK? What should I watch for, what will tell me that the child is stressed or tired and needs a break? What is the child's "Uh-Oh Threshold?")
- Organizing developmental goals and strategies as a tier system
    - Traffic light-green, yellow, red; parent/caregiver will assess the child in the first few minutes of the home visit and choose a tier (color)
    - The concept addressed by the goal is set up with strategies labeled with the 3 tiers/ colors, all strategies are addressing the same goal but require different amounts of energy to be used

Planning for home visits when the child's baseline is variable

- Putting the tier system into practice
    - Identify goal, organize strategies by color: Green-high to moderate energy; Yellow-moderate to low energy; Red-low to no energy.
    - Activity: Goals and Strategies for Connor
- EI documentation: supportive? confusing? Problems with interpretation
    - IFSP Goals and strategies …Where does your IFSP live? Is it posted on the wall, or kept in a folder with 10 other medical reports, buried in a drawer?
    - The original IFSP is printed and included with the developmental profile according to specific regulations. Then, it is the EI team's job to work with the family to determine the best way to meet the goals by incorporating the strategies into the family's daily activities.
    - Home Visit notes: who reads them? The child and family's support team may be very large. (EI, special educators for the deaf/blind/ASD, home nursing, medical teams, hospice/palliative care teams, inpatient services, etc.) How do we encourage communication without redundant documentation? (e.g. writing the same notes in numerous notebooks or communication books)

Encouraging "normalcy" despite equipment, and other medical intervention

- Everyone should be aware of basic info about accessories (name, function) and safety/ liability rules (What is my role and responsibility? What is someone else's role and responsibility? How will we work together as a team to meet the IFSP goals?)

Tubes, leads, wires, bags, head, shoulders, knees, toes … they are all part of the child's body; equipment is part of his personal space. Medical procedures are part of the child's routine. Hospital visits begin with stress, but the familiarity of the hospital crib, room layout, toys may provide comfort and continuity.

- Keep a journal with equipment: “This worked for us!” or “We learned something new about ____ today!” (Notice the positive perspective; equipment is an extension of the child’s body. It is not negative or positive, it just “is.”)

Resources for financial assistance/grants available to Mito kids

- Wish-granting orgs
- Mito-specific resources
- Medical transportation and lodging
- Medicaid waivers
- Equipment/service grants

Anticipating child’s transition from EI to public school services at age 3; depending on the child’s disease progression, health status, developmental gains, or regression, complexity of medical care at home, and time spent in the hospital or inpatient respite or sub-acute care facilities, this could be a significant and emotional milestone in their child’s care, with topics that could be extremely difficult for the family and team to discuss:

- What is the child’s awareness of his/her illness?
- What has the family and medical team decided regarding continued diagnostic testing, surgery, treatment?

What has the family and educational team decided regarding services and placement after age 3?

Accommodations made for eligibility, admission, annual/update, and transition testing:

- Easy fatigability: When developmental profile tests such as the Michigan and Mullen are administered, all subsections are typically administered sequentially or simultaneously. Due to the easy fatigability and activity intolerance that is a hallmark of mitochondrial sisease, this is likely impossible for the child to tolerate.
- Self-Care: This entire section assumes that the child has typical nutrition/hydration needs and feeding methods. Dressing and bathing is much more complicated when a child has tubes to accommodate. Elimination may be totally controlled by medical devices or procedures: ostomy bags, bladder catheterization. When a child is receiving enteral or parenteral nutrition and hydration, bladder control is almost always significantly delayed, especially if the child is receiving continuous fluids overnight. Consider the following test accommodations:
    - Child imitates tube feeding/medication with a syringe and a doll fitted with a feeding tube
    - Child may be dressed in clothing designed to protect medical devices so dressing/ undressing independently may be discouraged for medical reasons. Ask parent if there are parts of child’s routine that he/she can participate in that will show the same cognitive, social, and motor skills as dressing

    - Some lowest-level skills may never be achieved due to the child's medical condition; e.g. suck-swallow-breathe coordination for a child who is ventilator dependent and fed continuously through a G-tube.
- Dramatic fluctuations in symptoms, functioning, social interaction, all aspects of the child's life. Fluctuations occur by minute, hour, day, week, and may or may not be predictable or preventable.
    - Environmental factors can have an enormous impact on function. Carefully document the environmental conditions (temperature, time of day, presence/absence of distractions, familiarity with the testing location) and note any perceptible impact on the child's responses.
    - Fluctuations in function due to changes in energy are not only subjective. Children with Mito have shown dramatic fluctuations in objective testing such as vision and hearing tests, pulmonary function, muscle tone and strength, even the ability to maintain baseline temperature, pulse, blood pressure, and blood oxygen saturation. Obviously, this instability in basic physiologic function will profoundly impact the child's development and ability to interact with the world.
    - Are responses during testing typical of responses seen during home visits? Document your observations.
- Be sure to document the difference in performance between isolated and sequential skills. Is the discrepancy due to attention, focus, problem-solving, or fatigue?