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CARING FOR THE PEDIATRIC PATIENT AT HOME AND BEYOND

Cheryl A. Hall, PT, DHSc, PCS, MBA

“There are no seven wonders of the world in the eyes of a child. There are seven million.” ~ Walt Streightiff
COURSE OBJECTIVES

At the end of this course, participants will be able to:

1. List the five principles of child development.
2. Define the following terms: EI, IFSP, CPSE, IEP, CSE, and LRE as it pertains to service provision in children from birth to 21 years.
3. Identify at least three eligibility criteria for EI, CPSE and CSE services.
4. List at least three components of a comprehensive pediatric physical therapy evaluation
5. List the three cornerstones of facilitating parent involvement in home activity program.

AFTER THE ACUTE CARE PHASE: WHAT HAPPENS NEXT?
A retrospective study by Berry, Hall, Dumas, et al. (2016) compiled data to assess post-discharge status for 2,423,031 acute care hospital discharges in 2012 for patients ages 0 to 21 years in the US.

The study analyzed the national prevalence of:
- home health care use (HHC: visiting or private-duty home nursing)
- post-acute care placement (PAC: rehabilitation facility, SNF)
- characteristics of children discharged to HHC and PAC
- variation in use across states

RESULTS

- 122,673 discharges (5.1%) were to HHC and 26,282 (1.1%) were to PAC facilities.

- **Neonatal care was the most common reason (44.5%, n=54,589) for acute care hospitalization with discharge to HHC.**

- Non-neonatal respiratory, musculoskeletal, and trauma-related problems, collectively, were the most common reasons for discharge to PAC (42.9%, n=11,275).

- When compared with PAC, more discharges to HHC had no chronic conditions (34.4% vs 18.0%, P < .001) and fewer discharges to HHC had 4 or more chronic conditions (22.5% vs 37.7%, P < .001).

- Children with 4 or more chronic conditions compared with no chronic conditions had a higher likelihood of HHC use (11.0% vs 4.4%) and PAC (3.9% vs 0.8%).
COMPARATIVE CONDITIONS IN DISCHARGE PLACEMENT

Home Health Care
- The most common types of complex chronic conditions of children discharged to HHC:
  - gastrointestinal (16.6%, n = 20,310)
  - neuromuscular (11.5%, n = 14,104)
- The most common chronic diagnoses (of any complexity) included:
  - esophageal reflux (5.7%)
  - enterostomy (4.7%)
  - asthma (4.0%)
  - epilepsy (3.2%).

Post-Acute Facility Care
- Higher percentage of discharges to PAC were for children with:
  - multiple chronic conditions (65.1% vs 29.4%, \( P < .001 \)),
  - 1 or more complex chronic conditions (59.9% vs 30.7%, \( P < .001 \))
  - technology assistance (32.7% vs 7.3%, \( P < .001 \)).
- The most common chronic conditions included:
  - asthma (6.2%)
  - epilepsy (5.0%)
  - enterostomy (4.5%)
  - esophageal reflux (3.7%).

WHY IS USE OF HHC AND PACS LOWER IN THE PEDIATRIC POPULATION?
- Berry, Hall, Dumas, et al. (2016) hypothesized the following reasons:
  - Inadequate supply of home health nurses with pediatric expertise
  - Limited pediatric specialty centers/post-acute facilities
  - Insufficient payment for these services in children
  - Restricted access and approval by payers
  - Lack of validated guidelines to support implementation of services to children
Bridging the Gap
Best practice in the Home and School-based settings

YOUR RESPONSIBILITIES AS A PEDIATRIC PROVIDER

- Remember...you are a New York State mandated reporter!
- When child abuse or neglect is observed or suspected, the service provider must immediately notify The NYS Child Abuse and Maltreatment Register by telephone at 1-800-635-1522 and in writing within 48 hours of oral report.
- The Special Victims Squad of the Nassau County Police Department if the allegation involves non-familial abuse will be notified by telephone at 516-573-8055.
- The Director of the Early Intervention Program at the Nassau County Department of Health at 516-227-8648 (8:30 AM to 4:15 PM) and after business hours at 516-227-8685.

** Please check with your jurisdictions for additional rules and regulations, as these are the guidelines put forth by Nassau County DOH.
ADDITIONAL GENERAL INFORMATION: HOME VISIT DO’S AND DON’T’S

- An adult (parent/caregiver) must be present in the home at all times.
- Do not close the door or go into another area of the home without parent/caregiver’s permission.
- Do not eat or drink in the home
- Do not provide food to a child, unless authorized to do so by parent as part of the session.
- Do not bring other individuals to a session.

(Nassau County Department of Health. Early Intervention Best Practice Manual, 2007)

ADDITIONAL GENERAL INFORMATION: HOME VISIT DO’S AND DON’T’S

- Do not transport/drive a child or any family members anywhere.
- Do not take child/family members to your home.
- Always maintain good hygiene practices (wash hands, toys, equipment prior to session).
- Do not discuss other children or families
- Respect cultural needs of family with regard to care provision

(Nassau County Department of Health. Early Intervention Best Practice Manual, 2007)
ADDITIONAL GENERAL INFORMATION: OFFICE OR FACILITY-BASED SETTING

- Caregivers must be on-site at all times.
- Do not discuss child's status in a public area, in order to maintain confidentiality.
- Never leave a child unattended under any circumstances.
- Make use of rooms with two-way mirrors whenever possible.
- Never lock treatment room/area doors.

(Nassau County Department of Health. Early Intervention Best Practice Manual, 2007)

ADDITIONAL GENERAL INFORMATION: OFFICE OR FACILITY-BASED SETTING

- ALWAYS accompany child to restroom.
  - If the child requires a diaper change or assistance with toileting, it is the responsibility of the parent/caregiver to change a child's diaper or provide needed assistance. If toileting is a functional goal, a parent/caregiver must be available to participate.
  - Always maintain good hygiene practices (wash hands, toys, equipment prior to session).
  - Adhere to the “sick” policy of the facility, if a child comes in sick to his/her session.

(Nassau County Department of Health. Early Intervention Best Practice Manual, 2007)
ADDITIONAL GENERAL INFORMATION:
CHILD-CARE CENTER/SCHOOL-BASED PROGRAM

• The child and provider must be under direct supervision of
program staff at all times, when providing services in a
child-care center.

• Implement a method of communication:
  ▪ Center caregivers
  ▪ Teachers
  ▪ Parents, other caregivers (1:1 nursing, paraprofessionals)

(Nassau County Department of Health. Early Intervention Best Practice Manual, 2007)

continued

ADDITIONAL GENERAL INFORMATION:
CHILD-CARE CENTER/SCHOOL-BASED PROGRAM

• Any change in child’s medical status, significant life event
or change in family status should be noted and service
coordinator (EI) or social worker/designated school
administrator should be notified.

• If child requires a 1:1 nurse or other assigned
paraprofessional, that individual MUST accompany the
child to the treatment area and remain until the child has
been transported back to his/her designated classroom
area.

• Always accompany the child to the area where he/she is
to be returned.
GROSS MOTOR DEVELOPMENT: A QUICK REVIEW

0-12 months

- Newborn: fetal position (flexion)
- 1 month: lifts head in prone to clear chin
- 2 months: holds chin and chest up, prone on forearms
- 4 months: sits with support
- 5 months: rolls over (prone to supine)
- 6 months: rolls over (supine to prone)
- 7 months: sits alone
- 8 months: assumes hands and knees
- 9 months: stands with support
- 10 months: creeps on all fours
- 11 months: walks with support, stands alone
- 12 months: walks alone

15 months to 5 years

- 15 months: walks independently, creeps upstairs
- 18 months: walks backward, jumps with both feet, hurried walk/run, tosses a ball forward to a target
- 2 years: runs well, kicks ball with good force and direction, squats in play and rises to stand easily, walks down stairs non-reciprocally
- 2.5 years: stands on tiptoes, jumps with two feet together
- 3 years: walks on tiptoes, stands on one foot, rides tricycle, walks upstairs alternating feet
- 4 years: runs on tip toes, hops on one foot, broad jumps
- 5 years: skips

PRINCIPLES OF CHILD DEVELOPMENT

- Development is dynamic (interaction with the environment and how the individual responds to the environment)
- Culture (child-rearing practices, language, role of family members)
- Growth of self-regulation
- Children are driven to explore and master experiences in their environment
- Human relationships
- Individual differences in development in children
- The influence of experiences/opportunities on developmental pathways and trajectories
- Environmental and social risk exposure (poverty, other socioeconomic factors)
- The physical environment itself

(Adapted from Campbell, 2011, p. 880).
FACTORS AFFECTING CHILD AND FAMILY FUNCTION AND PARTICIPATION IN THE PEDIATRIC HOME CARE SETTING

Terminology of the Trade

- **Early Intervention (EI):** Those services that are provided between the ages of birth to 3 years old (Part C of IDEA)

- **Individualized Family Service Plan (IFSP):** Document that provides developmental levels, family needs, measurable outcomes, natural environments for services, duration of services, ISC, OSC, and transition plan while child is receiving EI services

- **Committee on Preschool Special Education (CPSE):** The committee that develops and monitors special education and related services for children ages 3-5 years old (before kindergarten begins).

- **Committee on Special Education (CSE):** The committee that develops and monitors SpEd and RS for school age children 5 to 21 years old.

- **Individualized Educational Program (IEP):** Document that provides developmental levels, types of services, measurable outcomes, location of services, duration of services, ratio while child is receiving CPSE or CSE services.
NATURAL ENVIRONMENT

- Settings where infants and toddlers, with and without special needs, and their families participate in everyday routines and activities that are important to them, and serve as important learning opportunities.
- Can include your home, places where child care is provided, playgrounds, restaurants, public transportation, libraries, supermarkets, places of worship, and other community settings.
- Are not just about places or locations, they are also about family routines and activities including family meals, bathing, bedtime, family celebrations, household chores, and visiting family and friends.


LEAST RESTRICTIVE ENVIRONMENT

“To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.”

COMMON DIAGNOSES IN CHILDREN REFERRED FOR EVALUATION

- Premature infants
- Children with ASD
- Congenital anomalies and syndromes
- Seizure disorders
- Torticollis/Erb’s Palsy
- Generalized hypotonia
- Hydrocephalus
- Metabolic Disorders
- Developmental Coordination Disorders
- Traumatic Brain Injury
- Mild, moderate, severe intraventricular hemorrhage
- Pre or peri-natal anoxia
- Meconium aspiration
- Chronic lung or heart disease
- Arthrogryposis
- Spina bifida
- Diagnosis of developmental delay
- Suspicion of delayed motor, cognitive, language/speech development
- Cerebral palsy

SERVICES PROVIDED

- Family education and counseling, home visits, and parent support groups**
- Special instruction (includes ABA for children who qualify)
- Speech pathology and audiology (including hearing aids)**
- Occupational therapy**
- Physical therapy**
- Psychological services**
- Service coordination**
- Nursing services**
- Nutrition services (including feeding therapy)**
- Social work services**
- Vision services**
- Assistive technology devices and services**

** Related Services are those additional services that are not categorized as “Special Instruction/Special Education”
EARLY INTERVENTION

- “The mission of the Early Intervention Program is to identify and evaluate, as early as possible, those infants and toddlers whose healthy development is compromised and provide for appropriate intervention to improve child and family development.”


MOTOR DELAYS

- According to the New York State Department Clinical Practice Guidelines, a motor delay can be identified by “mild to severe abnormalities of muscle tone, posture, movement, and motor skill acquisition.”
NYS EI PROGRAM GOALS

- **Support parents** in meeting their responsibilities to nurture and to enhance their child(ren)’s development.

- **Create opportunities for full participation** of children with disabilities and their families in their communities by ensuring services are delivered in **natural environments** to the maximum extent appropriate.

- Ensure **early intervention services are coordinated** with the full array of early childhood health and mental health, educational, social, and other community-based services needed by and provided to children and their families.

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NYS EI PROGRAM GOALS

- Enhance **child development and functional outcomes and improve family life** through delivery of effective, outcome-based, high-quality early intervention services.

- Ensure **early intervention services complement the child’s medical home** by involving primary and specialty healthcare providers in supporting family participation in early intervention services.

- **Ensure equity of access, quality, consistency, and accountability** in the service system by ensuring clear lines of public supervision, responsibility, and authority for the provision of early intervention services to eligible children and their families.

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GETTING THE BALL ROLLING: THE EI PROCESS

- Recommendations for referral can come from:
  - Parents
  - Pediatricians
  - Teachers, daycare personnel
  - Other family members
  - Other medical professionals
  - Other service providers

- Permission for referral to EI must come from parents/legal caregivers

GETTING THE DUCKS IN A ROW

- Parents
- Child
- Initial/Ongoing Service Coordinator
- Evaluation team (Special educator/Psychologist, PT, OT, ST/feeding therapist) performs the multi-disciplinary evaluation (MDE):
  - Evaluations can be conducted by each individual specialist or with 2 or more (arena style) based on parent preference and evaluator availability and preference.
  - Evaluations are conducted in home setting, daycare, or other setting, as requested by caregivers.

Other evaluations, services and specialists can be added during the MDE process or as determined at IFSP meeting.
WHO’S WHO IN THE EVALUATION PROCESS?

- Service Coordinator (Initial or Ongoing: ISC/OSC)
  - Responsible for initial intake and meeting with family prior for background information
  - Can be from the Department of Health or from contracted Agency
  - May or may not be the same person
- Special Educator/Psychologist
- Evaluation Generalist
  - Assesses all five areas of development (motor, communication, social emotional, adaptive and cognitive)
- Specialty area evaluators
  - Physical Therapist (Motor skills/development)
  - Occupational Therapist (Fine motor, visual motor, visual-perceptual, sensory)
  - Speech and Language Pathologist (receptive/expressive language, communication, feeding)

A FEW TIDBITS BEFORE THE EVALUATION…

- If the infant was born premature and less than 2 years (24 months) of age, she is assessed using her corrected/adjusted age.
  - Formula for determining corrected age:
    - date of evaluation-date of birth= chronological age
    - chronological age-weeks premature=corrected/adjusted age

<table>
<thead>
<tr>
<th>Example: DOE</th>
<th>Year</th>
<th>MONTH</th>
<th>Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOB</td>
<td>2017</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Chronological age</td>
<td>1 yr.</td>
<td>3 mo.</td>
<td>8 days</td>
</tr>
<tr>
<td>Weeks premature (8weeks):</td>
<td>2 mo.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected age</td>
<td>1 yr.</td>
<td>1 mo.</td>
<td>8 days</td>
</tr>
</tbody>
</table>
SOMETIMES THE OLD MATH WORKS BEST

Example: DOE
DOB
Chronological age: 0 yr. 11 mo. 26 days
Weeks premature (8 weeks): 2 mo.
Corrected age 0 yr. 9 mo. 8 days

MORE TASTEFUL TIDBITS IN EARLY INTERVENTION...

REMEMBER...

- If the child has had her 2\textsuperscript{nd} birthday, her corrected age is \textit{no longer used}.
  - She is now evaluated according to her chronological age (i.e., the age she would be based on her date of birth).
CPSE AND CSE PROCESS

Re-evaluation

Referral by parent, educator, physician, other professional

Evaluation

Development of IEP, placement and services to be delivered

Does child meet eligibility requirements

No services provided

The Assessment

What to include in the physical therapy evaluation
FUNDAMENTALS

- Reports must be written in parent-friendly language and in primary language spoken by family.

- If you are going to use medical terminology, you must include an explanation of what you are describing.
  - For example: “Popliteal angles (the angle between the thigh and lower leg when straightening the lower leg) were grossly assessed and greater than -20° bilaterally, which is consistent with findings of muscle stiffness in an infant of Sally’s corrected age.”

- Qualitative information is important and can be used to help justify services for a child, so watch for and document any anomalies or atypical movement patterns (tone, asymmetries, fisting of hands, use of excessive neck/upper trunk extension in prone prop before development of good head control).

- Avoid using words like “abnormal,” “spastic,” “autistic,” or words that communicate a diagnosis of any kind, unless one has been made by the appropriate medical personnel.

HISTORY AND BACKGROUND INFORMATION

- Maternal/pregnancy history
- Birth history
  - Delivery (C/S, NSVD, hospital, birth weight), APGARS, resuscitation, surfactant administration, mech vent, CPAP, O$_2$
  - Infant’s NICU course (This is important in HISTORY of any child, regardless of age)
    - Resuscitation, transfusions, history of apnea/bradycardia, hyperbilirubinemia, meds
    - Other conditions (cardiac, ROP, IVH)
    - Surgical interventions, test results (head US, Newborn hearing screening)
    - Rehabilitation services in hospital

- Discharge status
  - Medical follow-up, home care services, feeding/sleeping schedule
  - Subsequent illnesses (ear infections), hospitalizations
  - Immunization status
- Social history
- Motor milestones
- Family history of developmental delays
- Referral source and primary concerns related to referral to EI for evaluation
**APPEARANCE, BEHAVIOR AND SENSORY STATUS**

- Initial presentation of child upon arrival
- Child’s response to the evaluator(s)
- Was the evaluation conducted with other disciplines or alone?
- Was the evaluation conducted in English?
  - If not, was there an evaluator who could act as an interpreter, if English is not the primary language spoken at home?
- Physical observations of the child
  - Include assistive devices, if used, orthotics, corrective lenses, hearing aids, etc.

**APPEARANCE, BEHAVIOR AND SENSORY STATUS**

- Visual status (fix, follow/tracking, eye movements)
- Auditory status (behavior change/startle, localize to sound/name)
- Communication status (cooing, babbling, points, etc.)
- Sensory status/Pain status
- Was child able to tolerated therapeutic handling and position changes?
- Were the skills and behaviors typical for this child?
  - If not, what was atypical?
NEUROMOTOR STATUS

- Description of resting tone
  - Normal, high, high-normal, low, low-normal
  - Overall flexor tone (in infants)
  - Scarf sign (in infants)
  - Popliteal angles
  - Upper and lower extremity recoil (in infants)
  - Axillary slip (in infants)
  - Prone suspension (head, trunk and pelvis/leg position)

- Passive ROM (include extremities and cervical spine)
- Active movement (description of)
  - Active ROM
  - Smooth, jittery or tremulous
  - Symmetrical/asymmetrical (note asymmetries)**

- Infant reflexes, if appropriate
- Presence or absence of ankle clonus, cortical/indwelling thumb posturing
POSTURAL STATUS

- Resting posture
  - Head position (note infant reflexes/non-integration of primitive reflexes in older child)
  - Position of extremities (flexed, semi-flexed, extended, rigid)
  - Check prone, supine, when held at shoulder, sidelying, etc.
- Pull-to-sit (if appropriate)
- Head righting (neck flexion and extension righting in infants)
- Trunk righting (note positions)
- Equilibrium reactions (note positions)
- UE Protective reactions (directions and positions)

POSTURAL STATUS

- Postural preferences (head position, indwelling thumb, other)
- Sitting balance (describe quality, tripod/prop, tailor, with/without support, BOS, duration, activity/reaching outside BOS)
- Standing balance (describe amount of support required to maintain position, BOS, duration)
  - Note pes planus, calcaneal valgus/varus, genu valgum/varus, high guard posture, fixing postures for stability, etc.)
ASSESSMENT UTILIZED

- Include the standardized tool used for the evaluation
  - Alberta Infant Motor Scales (for EI from 0-18 months)
  - Peabody Developmental Motor Scales-2nd Ed.
- Parent report
- Clinical Observation
- Supplemental Checklist (Hawaii Early Learning Profile also known as the HELP Checklist for children 0-3 years and 3-6 years) as a secondary tool to support findings (Parks, 2007).
  - The HELP has shown to have good interrater reliability (>70%) in the area of gross motor assessment (Toland, Gooden, & Li, 2015).

ASSESSMENTS AND ELIGIBILITY

- Alberta Infant Motor Scales (AIMS, Piper, 1994)
  - 0-18 months
  - For pre and full-term infants “at risk”
  - Very sensitive to identifying motor delays in infants and the effects of early intervention (Van Hus, 2013 & Dumas, 2015)
ASSESSMENTS AND ELIGIBILITY

  - Children 0-6 years (used in EI for children 19 mos.- 36+ months)
  - Less time-consuming and more cost effective to administer
  - Able to assess gross motor skills only

- Other appropriate tests and measures used (special tests, modified TUG, modified Ashworth Scale etc.)
  - Age-appropriate
  - Population specific
GROSS MOTOR STATUS

- Primary means of mobility
  - Dependent, independent, rolling, crawling, creeping, ambulation, with/without assistive device, orthotics, with/without support and how much, if needed.

- Developmental Transitions
  - Describe the movement
  - Describe amount of assistance needed, if any, to complete the transition
  - Describe the quality of movement during the transition
    - For example:
      - Sally pulls-to-stand independently through half-kneel, using her lower extremities more than her upper extremities to complete the transition.
  - Indicate the presence or absence of age-appropriate skills
- Include a chart of standardized test findings

REPORTING STANDARDIZED TEST FINDINGS

AIMS

<table>
<thead>
<tr>
<th>Previous items mastered</th>
<th>Items Cracked in Window</th>
<th>Subscale Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prone</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Supine</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sit</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Stand</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Total score: 3  Percentile: <1%  t-score: >2.0 SDs below the mean

PDMS-2

The results of the Peabody Developmental Motor Scales 4th Edition were as follows:

- Stationary: 5  Percentile: 70  t-score: <2.0 SDs above the mean
- Locomotor: 3  Percentile: 1  t-score: >2.0 SDs above the mean
- Object Manipulation: 5  Percentile: 5  t-score: >2.0 SDs above the mean
- Gross Motor Quotient: 70  Percentile: 2  t-score: <2.0 SDs above the mean
CONDITIONS FOR AUTOMATIC ELIGIBILITY: EI

- Infants born under 1000 grams (extreme prematurity)
- Chromosomal abnormalities associated with developmental delay
- Syndromes and conditions associated with delays in development
- Neuromuscular disorder
- Clinical evidence of central nervous system (CNS) abnormality following bacterial/viral infection of the brain or head/spinal trauma
- Hearing impairment (a diagnosed hearing loss that cannot be corrected with treatment or surgery)
- Visual impairment (a diagnosed visual impairment that cannot be corrected with treatment including glasses or contact lenses or surgery)
- Diagnosed psychiatric conditions, emotional/behavioral

New York State Department Of Health. EIP Transition Guidance - Programmatic Eligibility for Early Intervention and Preschool Special Education.

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CONDITIONS FOR AUTOMATIC ELIGIBILITY: CPSE

- Autism
- Deafness
- Deaf-blindness;
- Hearing impairment; (not covered under the definition of deafness),
- Orthopedic impairment (caused by congenital anomalies, disease, or impairments from other causes);
- Other health impairments (including but not limited to heart condition, tuberculosis, sickle cell anemia, asthma);
- Traumatic brain injury (acquired); and,
- Visual impairment

New York State Department Of Health. EIP Transition Guidance - Programmatic Eligibility for Early Intervention and Preschool Special Education.
SUMMARY

- Include the age, gender, diagnosis, reason for referral, and general physical findings of the evaluation.
  - Sally is an eight-month six-day-old little girl (corrected age, if necessary) diagnosed with hypotonia, referred for evaluation secondary to concerns related to decreased muscle tone and feeding concerns who presents with postural delays and delays in age-appropriate gross motor skills.

SUMMARY

- Include test scores and statement of clinical opinion.
  - “Based on test scores and clinical opinion, Sally demonstrates a delay of 33% in the physical domain. In addition, as per the AIMS, Sally demonstrates gross motor skills to be -2.00 SDs below the mean, and based on clinical opinion in conjunction with standardized scores, the presence of markedly low muscle tone decreases Sally’s ability to interact with her environment in a manner consistent with her chronological age. As per the Hawaii Early Learning Profile, therapeutic handling, clinical judgment, and parent report, Sally demonstrates abilities at the 4-5-month level.”
SUMMARY (continued)

- Include information provided in New York State Department Of Health Division Of Family Health Bureau Of Early Intervention. *Clinical Practice Guideline: Report of the Recommendations Motor Disorders, Assessment and Intervention for Young Children (Age 0-3 Years) for EI.*

SCREENING VERSUS STANDARDIZED TEST

- Assessments should be chosen based on:
  - Age of child
  - Functional abilities if such a tool is available
  - Time to administer
  - Cost-effectiveness
  - Feasibility to conduct in the testing environment
  - Screening versus standardized
    - Screenings will determine if the child should be referred for formal assessment
      - For example, Denver Developmental Screening Test II
ELIGIBILITY REQUIREMENTS

### Functional Areas Assessed

- A significant delay or disorder in one or more functional areas
  - Cognitive
  - Language and communicative
  - Adaptive
  - Social emotional
  - Motor development

### Eligibility by numbers

- A 33% delay in one functional area or a 25% delay in each of 2 (or more) functional areas.
- A score of 2.0 SD below the mean in one functional area or a score of 1.5 SD below the mean in each of 2 functional areas

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KEEPING UP WITH THE PROCESS

**EI**

- Progress reports are completed every 6 months
- Re-evaluations by providers occur once a year.
- Transition meetings are held prior to the child’s 3rd birthday to determine the child’s eligibility for CPSE (preschool services)

**CPSE**

- Progress notes (each time a child is seen)
  - Be aware of Medicaid guidelines
  - Times of encounter cannot overlap with other related-service providers
- Annual assessments
- Transition from CPSE to CSE occurs for the child’s entry into their school district (usually Kindergarten).
Objective Development and Program Planning

The road to progress

GOAL WRITING

- One word…

FUNCTION
SHIFTING THE FOCUS FROM DISABILITY TO FUNCTION

- ICF (International Classification of Functioning, Disability, and Health)

  ![Diagram of ICF model]

  (World Health Organization, 2001)

GOAL FORMULATION: EI

- Usually submitted with the assessment
- About 5-6 goals with a timeframe of about 6 months
- Goals are functional and developmentally appropriate, which in some cases, does not mean age-appropriate, depending on the child’s current functional status
- Should always include a statement on caregiver independence in executing a home activity program
GOAL FORMULATION: CPSE/CSE

- Usually via databanks
  - IEP Direct
  - Requires an account
- Measurable IEPs need the following:
  - **Audience**: Child’s name
  - **Behavior**: will walk from the classroom to the cafeteria 200 feet…
  - **Condition**: using his assistive device (walker, forearm crutches)
  - **Degree**: without falling
  - **Evidence**: in two minutes or less
  - **Timeframe**: By the end of the school year

CARE PLANNING AND FAMILY INVOLVEMENT

A systematic review conducted by Benzies, Magill-Evans, Hayden, & Ballantyne (2013), assessed the psychosocial effects of parent education on stress, depression, anxiety, self-efficacy, and sensitivity and responsiveness in mothers with premature infants.
CARE PLANNING AND FAMILY INVOLVEMENT

Findings were as follows:

- Overall, mothers who were provided with psychosocial support, which included parent education and therapeutic developmental support for their infants were less depressed, less anxious, more self-efficacious.
- Less of an effect was noted on their levels of anxiety and sensitivity and responsiveness.
- Positive short-term effects on child development.

Conclusion

“Positive and clinically meaningful effects of early interventions were seen in some psychosocial aspects of mothers of preterm infants.”

(Benzies et al., 2013)

THE IMPORTANCE OF FAMILY INVOLVEMENT

- A study by Dunst, Bruder and Espe-Sherwindt (2014) found that the setting and context in which EI services were provided was very influential on the involvement of the parents.
THE IMPORTANCE OF FAMILY INVOLVEMENT

**CONCLUSIONS**

- Parents were more likely to be involved in their children’s early intervention when services were provided entirely or partly in the families’ homes.
- In contrast, parents were less likely to be involved in a capacity-building manner (as per IDEA, Part C) when their children’s early intervention was provided entirely outside the families’ homes.
- This study also shed light on the need for professional staff training on how to improve parent involvement in sessions.

(Dunst et al., 2014)

THE CORNERSTONES OF PARENT INVOLVEMENT

An earlier systematic review by Jansen, Ketelaar, & Vermeer (2006) examined how parents are influenced by participation in their child’s therapeutic program.

- This study found that some, but not all, parents are positively influenced by participation in their child’s program.
- For those who wanted to be more involved, the authors noted the following:
  - A positive parent-therapist relationship
    - Therapists need to include the parents as partners to increase compliance
      - Include parents in goal-setting, evaluation of goals and home program scheduling and content
  - A focus on family function and ease of integration of the HEP into the family lifestyle
  - Parental networking and contact with other parents of children with disabilities
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  (Jansen et al., 2006)

PROVIDING PEDIATRIC SERVICES IN THE HOME ENVIRONMENT

- A recent paper by Catalino, Chiarello, Long, T., & Weaver (2015) discussed professional development for physical therapists providing EI services.
  - The study identified reasons for variability in preparation for EI service provision
    - Variability in curricular content and contact hours in pediatric practice during PT education.
    - Lack of skills “to provide services using a primary service provider approach, engage in family capacity building, or work in isolation and/or as a team member in the natural environment.”
    - Lack of uniformity of requirements between state/county agencies
    - Difficulty generalizing the concept of interdisciplinary teamwork into the pediatric home-based setting.
SPEAKING OF THE INTERDISCIPLINARY TEAM

- Petit & Patterson (2014) studied the self-efficacy of teachers who provide home-based special education services.
  - This study revealed that teachers who received training, via a teacher preparation or certification program, a school district or agency, or a conference or workshop or any combination of more than one, had perceptions of better self-efficacy than those teachers who did not have specialized training.
  - This survey-based study also found that 75-80% of the teachers providing services did not have training on how to provided education services to this special population and nearly 70% of educators reported their districts did not have training services.

THE INTERDISCIPLINARY TEAM

- The majority of children seen for home-based services were serious or chronic illness (44.6%) and short-term medical condition (31.5%). The remaining students were at home due to disciplinary violation (7.6%).
- One of the recommendation that came from this study is that districts and agencies develop guidelines, manuals or handbooks and written materials could address issues including safety.

(Petit & Patterson, 2014)
CARING FOR THE MEDICALLY FRAGILE CHILD AT HOME

- Schedule therapeutic interventions around medical interventions to maximize treatment.
  - Respiratory treatments
  - Feedings/meals
  - Medications
  - Sleep-wake schedule
  - Other providers

An important aspect of care is coordinating care with the family and other members of the **interdisciplinary team**.

- Treatment should be administered as tolerated by the child.
- Be sure to discuss any status changes with family, nursing.
- Review flowsheets, if available.
- Observe child’s state and monitor vital signs, if able.
- Consider interventions based on child’s overall state and tolerance to activity.
CARING FOR THE MEDICALLY FRAGILE CHILD AT HOME:
STARTING WITH THE BASICS

- Positioning
  - Proper positioning can:
    - Maintain child safety and comfort
    - Preservation of skin integrity
    - Increase attention during learning-based and functional activities
    - Improve postural control and respiratory function
    - Improve mobility during tasks as needed

continued

Positioning (continued)
- Instructing parents, nurses, teachers, and other team members in positioning the child to achieve maximal benefits of interventions is a vital role of the physical therapist in the home environment.
- Use of adaptive equipment (chairs, standers, rolls, wedges)
- Easy follow through
- Post guidelines at bedside
CARING FOR THE MEDICALLY FRAGILE CHILD AT HOME

- Passive range of motion
  - Caregivers can be instructed in safe method to carry out PROM and increases consistency in follow-through.
- Active range of motion
  - Can be done through play and functional activities
- Breathing exercises
  - Bubbles for young children
  - Other age-appropriate activities for older children (diaphragmatic breathing, throwing a ball, etc.)
- Transfers, as functionally appropriate
- Developmental transitions, as functionally appropriate
- Gross motor skills
  - Appropriate to child’s functional level
  - Use of assistive devices/adaptive equipment, if needed

CARING FOR THE MEDICALLY FRAGILE CHILD AT HOME: PLAY-BASED INTERVENTIONS

- Use toys, games, manipulatives, adapted equipment to accommodate physical function
- Modify based on cognitive function
- Integrate sensory materials, if appropriate
- Use therapy balls, wedges, rolls, etc. for positioning to facilitate function

Image courtesy of: http://tccl.rit.albany.edu/knilt/index.php/Play_Based_Learning
CARING FOR THE MEDICALLY FRAGILE CHILD AT HOME:
PARTNERING WITH CAREGIVERS

- Caregivers can be instructed all activities as determined by the physical therapist.
- Clear schedules for position changes, donning and doffing orthotics, braces, splints should be visible at bedside and documented.
- Proficiency of caregivers in performing specific activities MUST be documented.
  - Be sure that you have seen the designated caregiver perform those activities you have deemed them to be able to carry out and indicate that in documentation.

OTHER ISSUES RELATED TO PEDIATRIC CARE

- Childhood obesity
- Children with:
  - Cardiopulmonary conditions
    - s/p organ transplants
    - Cystic Fibrosis
  - TBI, SCI
- Young adults with disabilities
  - The transition to:
    - Functional training for jobs
    - Post-secondary education
    - Independent living, group home community
CASE STUDY

John Jones

John is a 20-month-twenty-two-day-old little boy (corrected age of 19-months 4 days) born at University Hospital via Cesarean section after a 33 1/2-week gestation.

ADJUSTING FOR PREMATURITY

- DOB: 7/25/15
- Date of Assessment: 4/18/16
- Weeks premature: 40-33.5 = 6.5 weeks (1 month 18 days)
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<table>
<thead>
<tr>
<th>Chronological age</th>
<th>1 year</th>
<th>8 mos.</th>
<th>22 days</th>
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<tr>
<td>Prematurity Adjustment</td>
<td>--</td>
<td>1 mo</td>
<td>18 days</td>
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</table>

<table>
<thead>
<tr>
<th>Corrected age</th>
<th>1 year</th>
<th>7 mo.</th>
<th>4 days</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>19 months</td>
<td></td>
<td>4 days</td>
</tr>
</tbody>
</table>

CASE STUDY: JOHN JONES
HISTORY AND BACKGROUND

- Prenatal history was remarkable for intrauterine growth restriction (IUGR) and oligohydramnios. John weighed 4 lbs. 12 oz. at birth. John’s hospital course was unremarkable with the exception of hyperbilirubinemia, requiring phototherapy. John did not require ventilator support. Head ultrasound was normal. John passed the newborn hearing screening. He remained in the NICU for 10 days and was discharged to home without incident. There were no subsequent hospitalizations or illnesses. Immunizations are up-to-date.

- Mrs. Jones reported John’s early gross motor milestones to be relatively within normal limits. He currently receives Speech/Feeding Therapy twice a week through Early Intervention. Mrs. Jones reported that she is concerned about John’s gross motor development, balance and postural control.
APPEARANCE/BEHAVIOR/SENSORY STATUS

- John was seen at his daycare setting for this evaluation. His mother was present throughout the evaluation. The physical therapy evaluation was conducted in English. John was active, alert, and social. He transitioned easily from the playground with this evaluator. John demonstrated a social smile and was easily engaged in activities. John interacted sweetly with his parent and this evaluator. John demonstrated intact visual and auditory status, responding appropriately to visual and auditory stimuli and localizing to his name. He tolerated therapeutic handling, but did not like to be in supine, rising up toward sitting immediately. Mrs. Jones reported that John eats a variety of foods, but prefers crunchy foods. He enjoys bath time and brushing his teeth.

- Mrs. Jones reported that John is just beginning to say single words/label familiar objects (“dog,” “dada”), but communicates his needs primarily through pointing and bringing his parent, by the hand, to what he wants. He was easily soothed when held by his caretaker in the classroom.

- Mrs. Jones stated that this evaluation was an accurate reflection of John’s abilities.

ASSESSMENTS UTILIZED

- Peabody Developmental Motor Scales- 2nd Edition
- HELP Checklist
- Parent Report
- Clinical Observation
NEUROMOTOR STATUS

- John demonstrated **low muscle tone** in his hips, knees, and ankles with passive movement. **Mild hypermobility** was noted in both knees and ankles. **Popliteal angles** were full (the angle between the thigh and lower leg when straightening the lower leg), which is a finding consistent with the presence of low muscle tone. **Passive movement** throughout both upper extremities was full and muscle tone appeared to be low-normal throughout. **Active movement** was full throughout all joints and strength appeared within functional limits as determined by John’s ability to move all extremities purposefully and symmetrically against gravity. No **clonus** (ankle tremors) could be elicited.

POSTURAL STATUS

- John demonstrated consistent **head and trunk righting** reactions in all positions. Upper extremity protective reactions were present and consistent to the front, the sides and inconsistent to the rear when in sitting; however, John did not use his hands to abdominal to try to keep himself from falling backward.

- John demonstrated **equilibrium reactions** in supine, prone, sitting, and on all fours. These reactions are inconsistent in standing and during ambulation and just emerging, albeit very inconsistent, in hurried walk/running at this time.

- John depended upon **postural tone and “stiffening”** of his legs to prevent his from falling backward when in sitting and standing.
POSTURAL STATUS (continued)

- **Static sitting balance** was noted to be good, maintaining position without falling over; however, in **dynamic sitting**, John demonstrated delayed protective reactions and righting reactions. **Balance in an upright static standing** position is steady at this time; however, balance is diminished with **dynamic movement in standing** (walking/hurried walking).

- John demonstrated bilateral pes planus (flat feet) and calcaneal valgus (weight bearing on inside of foot resulting in John taking increased weight on the inner aspect of his heel bone). This is most likely due to the presence of low muscle tone. No postural preferences or deviations were noted.

GROSS MOTOR STATUS

- John's **primary means of mobility** was independent ambulation. John was able to **transition through the developmental sequence** (rolling, assume and maintain sitting, and assume and maintain standing). However, the transition to stand was completed quickly via bear stance in order to use momentum rather than graded control, making the transition a rather unsteady one.

- John was unable to **toss a small ball forward** and did not attempt to **kick a stationary ball**, this is most likely due to delayed postural/balance reactions.

- John was able to ascend the **stairs** via non-reciprocal creeping. He also ascended, step-to-step, with both hands held; however, he would not descend on his hands and knees, but did so with both hands held, as indicated above. John was very unsteady when attempting to ascend/descend the stairs in standing, requiring handrail assist and light contact guard and close supervision for safety.

- John was not observed to fall during activities, but was noted to be very unsteady on uneven surfaces and/or with increased speed of dynamic standing activities.
INTERPRETING STANDARDIZED TEST SCORES

The results of the Peabody Developmental Motor Scales-2nd Edition were as follows:

<table>
<thead>
<tr>
<th>Component</th>
<th>Standard Score</th>
<th>Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stationary</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>Locomotor</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Object Manipulation</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>

Gross Motor Quotient: 76
Percentile rank: 5
z-score: -1.60 SDs

Question: Based on the Early Intervention, criteria, does John meet the requirements for eligibility for services? Why or why not?

He does meet the criteria for EI eligibility because he already receiving one service (ST), so he only needs to demonstrate a 1.5 SD delay. John has a -1.6 SD delay. (slide 59)

SUMMARY

John is an adorable 20-month twenty-two-day-old little boy (corrected age of 19-months 4 days) who presents with gross motor and postural delays. Based on test scores and clinical opinion, John demonstrates a delay of 25% in the physical domain. In addition, as per the Peabody Developmental Motor Scales-2, John demonstrates gross motor skills to be -1.60 SDs below the mean, and based on clinical opinion in conjunction with standardized scores, the presence of markedly low muscle tone decreases John’s ability to interact with his environment in a manner consistent with his chronological age. As per the Hawaii Early Learning Profile, therapeutic handling, clinical judgment, and parent report, John demonstrates abilities at the 11-13-month-level.
GOALS

- John will be able to ambulate independently on outdoor surfaces (grass, sand) without loss of balance/falling for distances of greater than 20 feet.
- John will be able to assume standing in the free floor through ½ kneeling with graded control 100% of the time.
- John will be able to ascend/descend one flight of stairs in standing with the use of the handrail, using a step-to-step pattern.
- John will be able to toss a small ball forward for a distance of at least two feet when prompted.
- John will walk into a medium-sized ball when attempting to kick it two out of three times.
- Caregivers will be independent in performing a home activity program.

PLAN OF CARE

- Frequency and time determined by EI/School district committees.
  - Found on IFSP for children in EI
  - Found on IEP for children in CPSE/CSE
### PLAN OF CARE

**Objectives/Goals**

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**Interventions**

- Ambulation on uneven surfaces, inclines, mats, pillows, sand, grass
- Practice the transition by retrieving objects from the floor (puzzle pieces, legos, etc) to complete an activity.
- Practice stair climbing in the home/outside or practicing climbing a single step, using a small bench.
- Throwing activities can include catch, basketball, knocking over objects, throwing at a target.
- Kicking activities can include use of plastic bottles (bowling pins), soccer type play.
- Caregiver instruction in home program with illustrations.

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**TAKE IT FROM THE EXPERTS…**

“Play is often talked about as if it were a relief from serious learning. But for children, play is serious learning. Play is really the work of childhood.”

~Fred Rogers
REFERENCES


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