Opening doors to discoveries

Rettsindrome.org

Rett Syndrome Symposium
June 24-26, 2014
Westfields Marriott Washington Dulles, Chantilly, VA

FAMILY CONFERENCE
CDKL5

Opening Doors to Discoveries...

IFCR’s 2nd International
Family Conference
June 26-28, 2014
Washington, D.C.
Introducing...

Sarika U. Peters, Ph.D.
Valerie Owen, Ph.D.
Susan Lee, M.A. and Parent
Mickie McCool, Parent

IEPs and School Placement: Exploring Perspectives Empowers the Parent

June 28, 2014
Chantilly, VA
Introducing...

Sarika U. Peters, Ph.D.
Vanderbilt University, Vanderbilt Kennedy Center for Research on Human Development

Psychological Assessment
June 28, 2014
Chantilly, VA
Why get an assessment?

• Formal, individual evaluation of a child to establish/confirm diagnosis that leads to recommendations for intervention.
• Recommendations for home/school based on results of evaluation.
• Insurance coverage for outside services and supports!
• Baseline data to begin interventions/clinical trials (and post-intervention data)
Approaches to “testing”

• Most traditional assessments use standardized tools
  – A test that is administered and scored in a “consistent” manner
  – Often used in clinical trials – pre-post comparisons using “recognized” tools

• Norm-referenced test
  – Measures if they did “better or worse” than other people who took the test.

• Why can’t it be individualized?
  – How can they tell if things are being modified the same way for each child?
Broad domains of functioning – Complex interactions!

- Cognition
- Language
- Motor Skills
- Affect, Personality, Behavior
- Family Functioning/Interactions
- Adaptive Behavior
- Activities of daily living
- Medical issues (pain, respiratory infections, GI)
Special Considerations for RTT

- Adapted assessments – how will they assess what your child can do?
- Can they use an assistive device/PECS cards as part of the testing?
  - If you use a device (picture symbols, etc.) at home – have them observe what your child can do with it
  - What are the differences in scores when the device is incorporated?
- Sit in if you can! It helps interpret word approximations, gestures, behaviors, etc.
Commonly used standardized test instruments (overall development)

- Mullen Scales of Early Learning
  - Birth-68 months (chronological age)
  - Routinely used beyond the normative age range
  - Assesses visual reception, fine motor, receptive language, and expressive language skills
  - Most tasks are untimed
  - Used as an “outcome” in clinical trials/studies
- Involves several manipulatives
“Nonverbal” cognitive instruments

• Leiter-III
  – Several manipulatives – involves hand use

• Universal Test of Nonverbal Intelligence
  – Several manipulatives – involves hand use

• Conventional “IQ” measures are not recommended in RTT
  – WISC, DAS, Stanford-Binet, etc.
Receptive language

- Peabody Picture Vocabulary Test – IV
- Measures understanding of words/vocabulary
- Ages 2 ½ - 90
- “Motor free”
- Can be adapted
  - Non-standardized but may be a better reflection
  - Incorporate other methods for responses (eye gaze, etc.)
- Receptive language - better estimate of “cognition” in RTT and RTT-related populations?
Behavioral Assessment

• Behavioral concerns interfere with functioning and/or performance
  – Anxiety, depression, self-injury
  – Manifestations of pain/medical issues?
  – Important to assess to guide treatment
• Rett Syndrome Behavior Questionnaire
• Aberrant Behavior Checklist
• Observations
  – Video samples of behaviors
• Need functional behavioral assessments
Parent-report measures – Adaptive behavior

- Functional Independence”
- Vineland Adaptive Behavior Scales – II
- Adaptive Behavior Assessment System (ABAS-II)
- Scales of Independent Behavior – Revised
- Teachers can complete
- All scales measure several domains (Communication, Practical Academics, Self-Care, Home Living, Socialization, Community Use, Self-direction, Health & Safety, Leisure, Work)
Reports/Summaries

– Balance parent reported skills, teacher report, and direct observations in assessment
– Note strengths as well as areas of need
– Note differences in performance by modality (i.e. visual, auditory, etc.)
– Tangible recommendations that can translate to goals
Introducing...

Valerie Owen, Ph.D.
National Louis University

The basics of the IEP and what gets in the way of the process

June 28, 2014

Chantilly, VA
Major components of an IEP?

• Present Level of Performance
  – Drawn from all assessment information and key to developing goals

• A statement about how the student’s disability affects her involvement in the curriculum

• Goals/short-term objectives/benchmarks
  – There are no “good Rett Syndrome goals”
  – They must be individualized for each student
Major components of an IEP?

- Goals/short-term objectives/benchmarks must be meaningful and measurable

- Inadequate goal:
  - Mary will improve in reading comprehension.

- Better goal
  - After reading a short story, Mary will indicate the main idea of the story by selecting the correct picture representation for 8 out of 10 stories.
Major components of an IEP?

- How progress on the goals will be measured
  - Monthly/quarterly/what mastery means
- Special Education, related services and supplemental aids
- Program modifications, accommodations or supports
- Other
  - Functional Behavior Assessment/Behavior Intervention Plan
  - Transition plan
What gets in the way?

Developing and implementing IEPs are difficult because there are many realities, competition for resources, limitations and interpretations of the law, lack of knowledge about Rett Syndrome/CDKL5 and curriculum modifications and adaptations.
Misunderstandings and erroneous assumptions about Assessment and eligibility (labels)

- Assessments contribute to erroneous assumptions about student (Sar addressed this)
- Labels invite typological thinking.
- Labels (ID, Multiple, OHI) are necessary (unfortunately) to receive services, but the label does matter and can be changed.
Misunderstandings and erroneous assumptions about Curriculum, goals and progress

- Education only has to be “appropriate”, generally meaning making some progress
- Education program does not have to be the best (Rowley Case)
- Individualized Program does not mean individualized instruction
Misunderstandings and erroneous assumptions about Curriculum, goals and progress

• The IEP goals become the curriculum.
  – This significantly limits generalization and opportunities for incidental learning.
  – If the goals are met before the end of the school year, make sure they are working on something new.
Misunderstandings and erroneous assumptions about Curriculum, goals and progress

- General education teachers and some special education teachers don’t know how to accommodate students with disability generally and especially can be at a loss for students with Rett Syndrome/CDKL5.
Misunderstandings and erroneous assumptions about Curriculum, goals and progress

- We teachers don’t know how to teach the general curriculum to students with the most significant disability because, quite frankly, we never have. Effective strategies are just emerging.
- Low expectations and Attitudes about learning: She can’t learn it and doesn’t need to know it anyway.
Misunderstandings and erroneous assumptions about role of therapies

• By law, services only have to be provided if they are necessary for the student to benefit from the education program. If the district can show the student can benefit without a service, then it is not required to provide the service.
Misunderstandings and erroneous assumptions about Placement and Inclusion

- In the U.S., Disability and Special Education tend to be thought of as synonymous. This is not the case in other countries.

- Access to and progress in the general education curriculum only became part of the law in 2004.
Misunderstandings and erroneous assumptions about Placement and Inclusion

- Inclusion is a philosophy and not a strategy for instruction. All kids belong, are valued for their contributions and we make it work.
- Placement decisions happen at the END of the IEP process.
Misunderstandings and erroneous assumptions about Placement and Inclusion

- Many professionals see special education as a place and consider it beneficial to group “similar” students together for ease of service delivery.

Inclusion is not the law and there is conflicting litigation about the importance of “least restrictive environment” (Oberti v. BOE, Lindsey R.); the “constraints of inclusion” and the deference owed professionals (Beth B.)
Misunderstandings and erroneous assumptions between you and your child’s teacher

• You are expected (or feel like you need) to be an expert in every area.

There are many, many good and devoted teachers, but there are sometimes challenges with the teacher. Unfortunately, the IEP about your child’s “deficits” and not about what the teacher should be doing (not the teacher’s IEP).

• The system tends to be set up to be adversarial. But there are effective strategies.
Introducing...

Susan Lee

Rett Syndrome:
A Teacher’s Perspective and Making Smooth Transitions

June 28, 2014
Chantilly, VA
Types of Educational Settings

- Inclusion
- Mainstream/ Resource
- Self-contained
- Specialized School/ Out-of District Placement

Educational setting is an IEP Team decision based on your child’s individual needs.
Special Education
Teacher Perspectives

• Nervous of the “unknown”
• Concerned
  – Lack of training
  – Lack of curriculum
  – Lack of materials and equipment/ knowledge of how to use them
  – Fear of medical issues
General Education Teacher Perspectives

• Nervous of the “unknown”
• Concerned
  – Flow of classroom
  – Acceptance by other students
  – Incorporating your child/ equipment into the classroom
  – Support from Special education staff/ Safety
Making for a Smooth Transition

• Share Materials/ Resources
• Meet with the TEAM before school begins.
• Provide Education and Support Networks
  ❖ Rettsyndrome.org Educator’s Network
  ❖ Rett University- webinars
  ❖ Bring in an expert
  ❖ Offer to do the “legwork”
• Transition to new schools/teachers
  ❖ joint transition meeting
  ❖ Tour school with familiar staff
Transition-Time: Preparing for the First Contact and Beyond

- Prepare the Staff- “All About Me” Book
- Note to Parents in Classroom
- Attend “pre-school” activities (orientation)
- Answer questions simply, honestly, but not medically or bringing extra attention
- Volunteer to help in the classroom
- Participate in school activities
- Attend out-of-school events
Introducing...

Mickie McCool, Parent

Getting to “Us”
June 28, 2014
Chantilly, VA
IEP Toolkit for Effective Advocacy

- Maintain good working knowledge of your rights, IEP content/structure and procedures
  - **Parental Concerns** - Don’t underestimate value!
    - As a matter of law, they “must be considered”!
    - By definition, they are non-negotiable
    - Do not be bashful! Be thorough, genuine and candid.
    - Read them aloud to the IEP team
- Develop knowledge of your IEP Team (e.g., anxieties, personality types, styles, “coalitions”, reputations within the team, interests, biases, district politics, etc.)
Gauging IEP Personalities & Attitudes

- The tyrannical administrator (failure to toe-the-line is career limiting)
- Team member gone rogue (lawless team member either doesn’t know, doesn’t care, or doesn’t care to know about IDEA requirements)
- The command-and-control freak (knows it all and resents / over-reacts to dissent)
- The sandbagger (opportunistically withholds key information)
- The smiling assassin (professes to concur with you, but actions undermine)
- The crystal tapper (chomping at the bit to leave)
- The serial “patronizer” (condescends habitually)
- The cowardly lion (completely agrees with you outside the meeting, but wilts at the meeting)
- Ms. Polly Anna (sugarcoats all that is worrisome and glorifies your child’s few successes)
- Other Mother(s) and “club” members
Getting to “Us”
(Solving the “us” versus “them” dynamic)

• Come prepared as an authority on your child
• Dress for the job (business casual attire, spit-and-polish conveys seriousness)
• Do not attend the IEP meeting alone!
• Make it personal – bring pics and anecdotes (“She’s in there!”)
• Draw valid parallels with typical children (e.g. desire to belong, have friends, etc.)
• Foster and co-opt other believers (enables partnering and collaboration)
Getting to “Us” (cont’d)

• Leave your comfort zone – interact outside IEP meetings
  – Invite them to visit your child at home (“How can…?”)
  – Invite them to a Rett Syndrome event
  – Pursue “off-the-record” conversations
  – Orchestrated informal IEP “pre-meetings” (dispels stereotypes and minimizes surprises)
  – Mine for common ground, similarities that strike a chord

• Listen ACTIVELY at IEP meetings
  – Ignore and disenfranchise the meeting “dominator” by engaging others, soliciting their input

• Don’t assume, don’t pre-judge
Getting to “Us” (cont’d)

• Be the “Policy Police” (expose and neutralize)
  – “always” and “never” statements presume one-size-fits-all, and they ignore the realities of Rett Syndrome

• Prioritize and know your bottom line
  – separate wants from needs, “must-haves” from “nice-to-haves”
  – know when to dig your heels in (“How can…?”)

• Be a reasonable / flexible problem-solver, but not a pushover
  – Be willing to improvise, think outside the box
  – Leave emotions at the door (easier when not alone)
  – Don’t get rattled; remain calm and in control
Getting to “Us” (cont’d)

• “We’re In This Together”
  – acknowledge / affirm teacher anxieties
    – you’ve been there!
  – openly praise actions of those that “get it”

• “Give Back” whenever possible
  – volunteer your time at unrelated school events (bring your daughter?), donate used equipment, devices, etc., to the school
Questions?