The Doctor goes to School

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Communication between parents, school teams, and health care professionals:

How good data-collection and information-sharing helps everybody….especially the student

Disclosures

- None

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The Doctor goes to School: Outline

- Part 1:
  - The current status of communication
  - Key questions that we should all be asking and addressing
  - Key data that we should all be collecting….and sharing
  - How to communicate about students with specific medical/behavioral conditions
- Part 2:
  - When adults disagree: What do you do when health care professionals, school professionals, and/or parents disagree with one another?
  - Diplomacy, therapeutic interviewing, and relationship-building

Current status of communication between schools and health care providers

- Missing or Inconsistent
- Fragmented or not comprehensive
- Not always effective or meaningful
- At times, unclear purpose/agenda

Why is ineffective communication a problem?

- Parents, health care providers, and school teams all need good information to make good medical and educational decisions
- Good information-sharing depends upon good communication. Good information does not get shared unless there's good communication
- Good communication is not a luxury. Children depend upon adults who share good information and who collaborate with one another

How can we improve communication?

- Communication improves when professionals communicate about what matters. Good communication depends upon advance agreement about
  - Key questions
  - Key data to be collected
- Good communication also depends upon making the questions and the data understandable to parents and share that information with parents …..
- **Parents automatically improve and enhance communication between professionals when they have good information to communicate about*

Routine key questions that we all need to consider:

- What diagnosis does this child have?
- What symptoms does this child have?
- What treatments are needed?
- What are the likely problems this student will have when participating at school?
- How successfully is the child participating?

Routine key data to collect

- We all need information about both symptoms and successes*
  - *Symptom = barrier or problem. What you want less of or what you want to remove.*
    - *Symptoms can be medical or behavioral*
  - *Participation = successes. What you want more of . The skills that you want to build*
    - *Basic Participation behaviors= Attendance and timely arrival at school*
    - *Complex participation: Speaking, listening, learning, socializing*

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Examples of data to collect : Symptoms and barriers

- Examples of medical symptoms/signs
  - Difficulty breathing
  - Vomiting/diarrhea
  - Vital signs: RR, HR, BP
  - Blood glucose
  - Height/weight
- Examples of behavioral symptoms
  - Inattention, hyperactivity, anxiety, aggression
  - Absences, tardies, lack of participation at school

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Examples of data to collect: Successes and skills

- Medical examples of good health (what you want more of)
  - Growth
  - Extent of good nutrition
- Behavioral examples of successes (what you want more of; the skills that you want to build)
  - Attendance
  - Timely arrival at school
  - Participation in classroom learning
  - Socializing with peers
  - Navigating the building independently
  - Academic learning

We all need to collect data numerically*

- When collecting data, always think of these basic descriptors of symptoms or 'problems':
  - Frequency of the symptom/behavior
  - Duration of the symptom/behavior
  - Severity of the symptom/behavior
- When collecting data, also collect information about participation
  - Frequency of absences, or frequency of attendance
  - Frequency of tardies, or frequency of on-time arrival
  - Capacity to complete work while in class (e.g. percentage
  - Grades (quality of work produced)

Communication about specific conditions

- Case presentation: Child with Neurological condition

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Communication for this case

- Question from school nurse:
  - *Do you have any medical recommendations for this child at school?*
- Answer from MD:
  - *Close observations*
  - *No restrictions*

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A more comprehensive way to communicate about any child with a specific condition

- Key questions that a parent would have for any child with a medical condition:
  - What condition does my child have?
  - What symptoms does my child have? Which symptoms should I monitor at home? Which symptoms should the school team monitor at school?
  - What treatments does my child need? Do any treatments have to be delivered at school? (prescriptions)
  - How do we maintain my child's safety? (Activity restrictions)
  - How do we promote my child's participation and assure effective progress?

Data-collection: symptoms and signs

- The treating clinician has to define which symptoms need to be monitored, as it varies by condition. For a neurological condition, symptom-data-collection could be
  - Seizures
  - Episodes of loss of consciousness
  - Episodes of being/seeming to be confused
  - Episodes of losing balance
- School teams can collect information about symptoms/signs
- Clinicians and parents can use this information to help make medical decisions in the clinic…but school teams can make use of this data also

Data collection: participation behaviors

- School nurses and school teams can collect information about participation behaviors
  - Basic participation includes
    - Attendance
    - Tardies
    - Participation in class
  - More specific examples of participation includes
    - Participation in PE
    - Navigating the building

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Data collection: participation behaviors

- Participation behaviors give the treating clinician an indication of the 'severity' of the child's condition
- Participation behaviors give the child's parents and school team information about effective progress and the quality of the child's IEP

What data or information do we have to collect about symptoms/signs?

- Answer: It depends. …However, data-collection for symptoms/signs are predictable
  - Vital signs
  - Growth parameters
  - Food intake
  - Urine output
  - Seizures
  - Episodes of Loss of Consciousness
  - Hyperactivity
  - Aggression
  - Anxiety

Symptoms and participation

- When school teams and clinicians consider both symptoms/signs and participation behaviors, they can work together to
  - Assure safety
  - Improve (medical) care
  - Improve (educational) care---improve participation at school
  - Document effective progress
- When school teams and clinicians share this information with parents, they empower parents to make good decisions for their child…and they also empower parents to facilitate the communication!

What data or information do we have to collect about participation and successes?

- Answer: It depends. However, the types of participation behaviors we need to consider are predictable. Examples:
  - Attendance, tardies
  - Classroom learning
    - Teacher-directed learning
    - Peer mediated learning
  - Physical education
    - Stamina
    - Coordination
    - Contact versus non-contact sports
  - Navigating the building; using the bathroom
  - Non-academic time
    - Cafeteria, playground
    - Special events
  - Field trips; auditorium/assemblies; lock-downs and fire drills

What constitutes good data collection?

- Good data collection means documenting the following
  - Frequency of symptom/interfering behavior…..and frequency of (successful) participation behavior
  - Duration of symptom/interfering behavior…..and duration of (successful) participation behavior
  - Severity of symptom/behavior (i.e. functional impact)

Activity restrictions

- How should physicians/ health care providers respond to the question of activity restrictions?
- Example:
  - Activity not allowed
  - Activity allowed with modifications
  - Activity allowed with supervision
    - Define 'supervision'
  - No activity restrictions/ participation as usual

Pause for reflection

The doctor goes to school, take 2

When adults disagree: What do you do when health care professionals, school professionals, and/or parents disagree with one another?

Reconciling differences of professional opinion

- Differences of opinion between professionals are common/expected.
- Professionals within and across agencies need to be able to reconcile differences of opinion
  - Differences of opinion are extremely difficult for parents to reconcile

Reconciling differences of professional opinion

- Start with good questions and good data collection.
  - What symptoms does this child have? Symptoms can be medical or behavioral
    - For which symptoms should data-collection occur?
  - How well is this child participating at school?
    - What data needs to be collected about participation?
    - For what activities (participation) should data-collection occur?

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Additional Cases for Discussion

- Case of 6-year old with Neurofibromatosis
- Case of a teenager with ADHD

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A 6-year old with NF

- Parent concern: My child needs an out-of-district placement!
- Case description:
  - Hypotonia
  - Global, mild cognitive impairment
  - Low muscle tone
  - Sensory sensitivities/disruptive behaviors

6-year old with NF

- What is the role of the health care provider?
  - Make suggestions for what key questions to answer and what data to collect
- What is the role of the school team?
  - Make sure that key questions are asked and good data –collection occurs

6-year old with NF

- How do we (health care and school professional) address the parent's concerns?
  - Make sure the questions and the data are understandable to parents
  - Make sure that the parents understand how to build an IEP
  - Make sure that parents understand the concept of LRE
  - Make sure that the parents know how to be a parent for this child

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6- year old with NF

- Pediatrician/ health care provider: Provide a good description of important symptoms to notice or monitor
  - Hypotonia
  - Sensory sensitivities
  - Mild global cognitive delays
- Pediatrician and school team: Make sure that there is good information about the child or student's participation
  - Academic learning
  - Classroom participation
  - Participation outside of the classroom/ outside of the school

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6-year old with NF: In-depth analysis

- Neurodevelopmental Foundations for Learning: A way to summarize the learning needs of students
  - Vision
  - Hearing
  - Motor skills
  - Executive skills
  - Emotion-management skills
  - Language skills
  - Social skills
  - Academic skills
  - Adaptive skills
- Using this format, it's possible to generate IEP goals, objectives, and accommodations

6-year old with NF: Know how to build an IEP

- Educational goals and objectives
  - *What does this child need to learn? What skills need remediation?*
- Methodologies needed
  - *How are professionals supposed to teach this child?*
- Professional staff needed
  - *Who is going to teach this child?*
- Site of education/ placement
  - *Where will this child receive his/her instruction?*

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6-year old with NF: Make sure the parents know how to be a parent for this child!

- What specialized parenting strategies might be needed to assure the following?
  - Having fun as a family
  - Sleeping
  - Eating
  - Routines
  - Rules
  - Friendships
  - Physical activity
  - homework

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Empower the parents

- Sharing key questions and sharing important data/information empowers parents
- Empowered parents can help bring a team together
  - Disempowered parents can fragment school teams
  - Disempowered parents can also fragment communication between the school team and the health care provider

An adolescent with ADHD

- Adolescent with ADHD
- Normal intelligence; 504 Accommodation plan in place
- Student "Never does his homework"
- *"The parents are not making sure that he gets his homework to school!"*

Adolescent with ADHD

- Be systematic in describing the student's symptoms
- Be systematic in describing the student's participation behaviors
- Identify important goals
  - Homework completion
  - Maintaining an organized bookbag
  - Etc.

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Adolescent with ADHD

- Identify what methods are needed
- Identify which adults should be doing what
- Find out what the parents are doing at home if you're concerned about their support at home

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Part 1: Major teaching points

- Medical providers can develop and answer key questions
  - What symptoms are the most important to consider?
  - What treatments are needed?
  - How is the child's participation likely to be affected?
- School teams (and parents) can ask key questions and collect key data
  - Symptoms or barriers: Frequency, duration and severity of both medical and behavioral symptoms
  - Successes and participation. How well is the child participating? Frequency and duration of successful participation
- Medical providers and school teams can share this information with each other…..and with parents

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Part 2: Advanced teaching points

- When there's confusion, disagreements, or conflicts:
  - Take a deep breath

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Part 2: Advanced teaching points

- When there are disagreements or when there's confusion, make sure that everyone understands
  - What the key questions are
  - What the data collection needs to be
- Make sure that everybody has (quantified) data to review
  - Data collected over time is the most useful
  - Anecdotal data is still a good place to start

Part 2: Advanced teaching points

- When there's confusion or disagreements
  - Move to a more advanced review of the child's strengths and needs (review of Developmental Domains)
  - Make sure that everybody understands the steps involved in building an IEP
  - Make sure everyone understand (a little bit) what it's like to live with a child with a disability
  - Have a discussion with the family about their experience living with a child with a disability….Help the family access specialists who can share strategies for how to teach routine home-related skills to a child with a disability