

# Communication, More Than a Marble Composition Book



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# Definition of Special Health Care

## Needs:

- CSHCN has defined in the 2001 National Survey of Children with Special Health Care Needs as “those who have or are at increased risk for chronic, physical, developmental, behavioral, or emotional conditions condition and who also require health and related services of a type or amount beyond that required by children generally.”



# Maryland's Stats:

- In Maryland there are 15.2% children with Special Health Care Needs compared to the National average of 12.8%

- Prevalence by Age: Maryland/ National

0-5	9.2%	7.8%
6-11	17.9%	14.6%
12-17	18.2%	15.8%



# Children Needing Referrals:

- In Maryland 26.6% compared to the National Average of 21.9% have problems getting referrals for specialty care.
- In Maryland 11.8% compared the National average of 11.0 do not have a personal doctor or nurse.



# Coordinating Care

- In Maryland 9.1% spend more than 11 hours per week providing or coordinating care. The National Average is 13.5%.
- Even though this is less than average it is time consuming for families.



# Affecting Employment

- 30.8% of the families in Maryland the condition of their child affects their employment, compared with the National average of 29.9%.



# Why are these Stats Important?

- The need to obtain referrals, so that the child can receive proper medical attention is essential for the child to be successful in school.
- The parent needs to be able to have a rapport with a physician or NP to help with the medical needs, since many children with special health needs respond differently to normal viruses etc.



## Continuation of Importance:

- If a parent is spending more than 11 hours a week trying to coordinate care this takes away time from just being a Mom or Dad.
- It is really more than 1 day of an average work day to coordinate the care.





# How this can create Barriers

- School team not understanding the medical condition of the child, and how the condition can impact learning.
- Not a sound understanding of medications, medical condition by both parties involved.
- School might not have a School Nurse on premise.
- Parents forget to communicate changes or only let the teacher know , never gets communicated to other team members.



## Barriers:

- Physicians write orders for related services based on medical needs not educational based needs.
- The Medical Model and Educational Model do not blend easily.
- Not every child has a REM Case Manager.



# Can this Problem be Fixed?

- Communication is essential for all parties involved in the care of the child with special health needs. So how can this be accomplished without adding more stress.



# Role of the Parent or Caregiver

- Have all your child's medical reports organized and in one section of a binder.
- Have your child's IEP's in order in the same binder.
- Keep a list of your child's current physicians phone numbers handy so that other family members can find them



# Role of Parent or Caregiver

- Make sure that you fill out the school's emergency cards with updated numbers and information.
- Have a current list of your child's medications and dosages as well as your child's weight.
- Keep the line of communication open with the school, especially if there is a change of your child's medical condition.



# School's Responsibility

- Communicate with parent's regularly concerning the child's educational progress.
- If the school doesn't understand the condition, they should ask for clarification. One child with CP is not the same as another.



# School's Role

- Make sure that there is an established method of making the whole team aware of changes of the child regarding health related issues.
- Understand that the parents of children with special needs have added burdens.
- Call in resources to help the team understand the child's medical condition.
- Make sure parents receive IEP goals on time to review prior to meetings.



# The Nurse's Role:

- Make sure that you establish a relationship with the family and REM case manager .
- You can be an advocate for the child
- If you have permission to speak with the MD you can help the MD know of changes.
- Many medications are XL or BID so the school might not be aware of medication changes, so try to ask that question.





# Working as a Team

- Try to establish trust among all parties.
- Keep the lines of communication open.
- Be understanding
- Keep the child's best interest in front.