

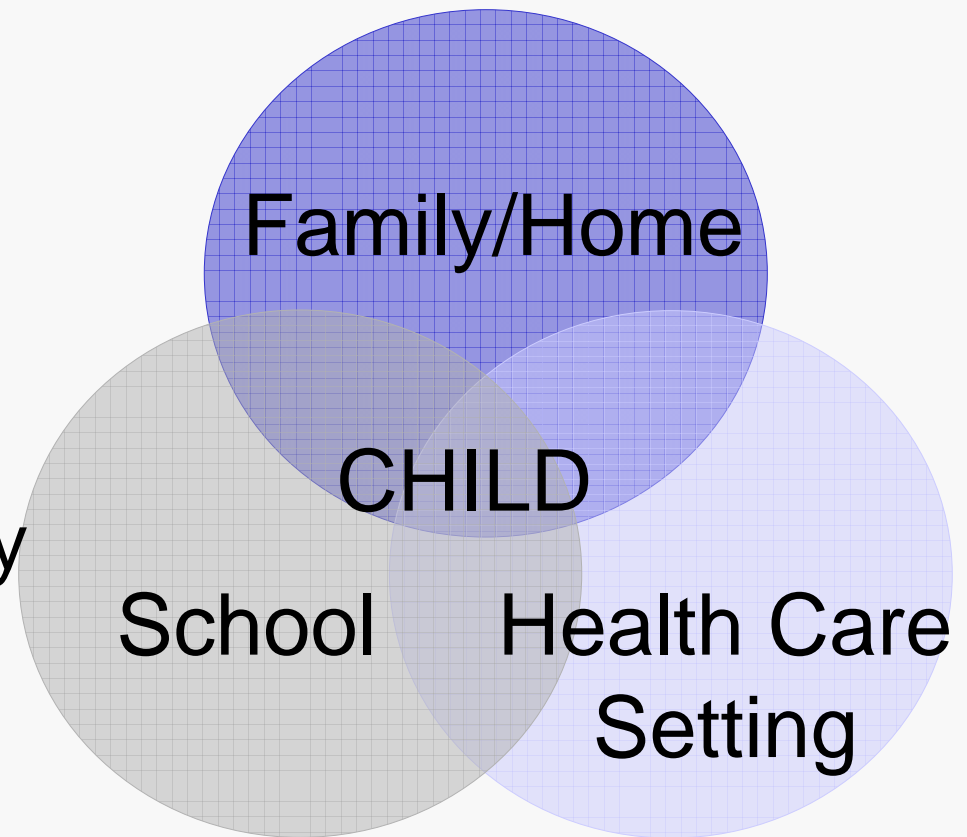
# ***Care of Children and Youth with Special Health Care Needs in the Schools***



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# Research Focus: Care of Children and Youth with Special Health Care Needs (CYSHCN)

- Document and address the needs of CYSHCN as they access and interact with multiple systems



# Why?



***“We recently received a child from another school district with a tracheotomy and feeding tube. I wasn’t trained for this. Can you help?”***

**School Nurse and UW –  
Madison School of  
Nursing Pediatric Nurse  
Practitioner program  
graduate.**

***“I have been really frustrated with [her] care...I just wanted one person or a team of people to be on the same page and develop a program and a plan for her.”***

**Parent of a child with special  
health care needs.**

# Background and Significance

- Since 1975, school districts have a federal mandate to provide free, appropriate public education to all children in the least restrictive environment.
- As a result, numbers of CYSHCN have increased dramatically in schools (Lear, 2007).
- Training programs haven't kept pace, creating a gap in the expertise of school nurses who care for CYSHCN as they transition between health care, home and school settings (Ireys et al., 1996).

## Specific Aims/Methods:

1. Document the challenges of providing care for CYSHCN across multiple settings.
  - ✓ Semi-structured interviews/national survey of school nurses.
2. Develop a training program (*SMOOTHs*) targeting school nurses who care for CYSHCN to address these challenges.
  - ✓ Interdisciplinary team review of interview and survey data (Adult Education, Special Education, Physicians, Nurses, Community Providers, Social Workers, Therapists [PT, OT, Speech and Language], Multimedia Technology specialists).
  - ✓ Develop content, scope, and sequence of *SMOOTHs*.
3. Implement a *SMOOTHs* pilot program in selected school districts.
  - ✓ Train random sample of nurses from surveyed schools, use clinical case studies/observation to compare outcomes.
4. Compare outcomes of CYSHCN whose care was coordinated by *SMOOTHs* trained persons with outcomes of children whose care was not.
  - ✓ Survey CYSHCN and parents to compare selected outcomes

# Where we are now

- Aim: Document the challenges of providing care for CYSHCN across multiple settings.
  - Project A: Semi-structured interviews with school nurses (completed)
  - Project B: Semi-structured interviews with families of CYSHCN (underway)
  - Project C: National survey of school nurses (underway)

# Research Project A

- *Documenting the Challenges of Caring for Children and Youth with Special Health Care Needs in the Schools: **School Nurse Interviews***
  - In-depth semi-structured interviews with 7 school nurses from large and small districts, urban and rural



# Identified Themes

- **Isolation**

- “Yeah, um, well there’s no one here but me (laughs) so in that we we’re kind of like out on the island”

- **Trust**

- “Well I think that their biggest concern is they’re basically handing their child over to people who don’t KNOW their child as well as they do. And I think, for MOST parents, there’s a lot of anxieties”

- **Communication and care coordination**

- “Well, I mean , if a child has a good health care plan ... then they get the dream you know? ... if they have pay for service medicaid, there’s no one to communicate with and say let’s look at the big picture, what’s going on with this child?”

# Research Project B

- ***Parents of Children and Youth with Special Health Care Needs: Documenting the Experience of their Child's Care in the School Setting***
  - In-depth semi-structured interviews with 10 families in 3 areas of the state: Milwaukee, La Crosse, Waukesha County



# Research Project C

- *Documenting the Challenges of Caring for Children and Youth with Special Health Care Needs in the Schools: **A National Survey of School Nurses***
  - Survey content based on results of interviews and research and clinical literature
  - Survey 2600 randomly selected members of National Association of School Nurses
  - The UW Survey Center will assist with the development of the survey instrument, the printing and mailing of the survey, and data entry of the results
  - January - April 2008

# Conclusion

- An in-depth knowledge of CYSHCN care can enhance service coordination, reduce stress on CYHSCN and their families, and improve outcomes.



# Acknowledgements

- Funding:
  - 2006 Robert and Caroll Heideman Research Award from the School of Nursing, University of Wisconsin
    - School Nurse Interviews
    - Family Interviews
  - The Palmer Foundation
    - A National Survey of School Nurses
  - National Institutes of Health (NIH), Institutional Clinical and Translational Science Award (UW-Madison) (KL2), Project Number: 1KL2RR025012-01
- Interview participants (school nurses and families)

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# ADHD GRANT STUDY

RENE' PETRITIS R.N.  
SOUTHWEST PEDIATRICS  
CHILDREN'S MEDICAL  
GROUP



# Why?

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- The AAP and AACAP recommend that clinicians establish a monitoring system to track the affects of medication treatment in children with ADHD
- It is also recommended that periodic, systematic follow-ups in early weeks of medication treatments be conducted so adjustments can be made in timely manners
- Studies indicate that successful treatment of symptoms of ADHD require collaboration between the patient, family and care providers

# Objectives

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- Improve care coordination of children with ADHD starting new stimulant medication
- Engage patients in the program who are currently on medication for ADHD and require closer monitoring
- Educate patients and their families about ADHD and their medications
- Maintain consistency in patient care among our practice

# Project Roles

- Dr. Christopher Schwake & Dr. Robert Rohloff: co-project coordinators/ physician advisors
- Five nurse care coordinators ( 3-RNS,2 LPNs)
- Medical home advisory panel at Southwest Pediatrics –assist in planning and advising
- Support from the Southwest Pediatrics staff



# Project Details

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- Identify patients who are starting new ADHD medications
- Assign nurse care coordinator to family
- ADHD folder given to family with explanation of contents
- Maintain log of all patients involved in study and contacts made after enrollment

# Folder Contents

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- Cover letter
- Care coordinator information
- Prescription refill procedure
- ADHD Monitoring and Medication Effects Form
- Reference websites

# Care Coordinator Information Form

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Dear Parent,

\_\_\_\_\_ will be your nurse care coordinator. She works at the clinic on (Monday Tuesday Wednesday Thursday Friday) between the hours of 8:30am-5:00pm. Please ask for your care coordinator if you have any concerns or questions about your child's ADHD medication. If you have urgent concerns, feel free to call on any day and someone will be happy to assist you.

In your folder you will find ADHD Monitoring and Medication Effects forms. These forms will be used to keep track of how your child is doing while on their medication, and to identify effects this medication may be having on him/her, whether positive or negative. Please use this form as a checklist to monitor your child because we will rely on your feedback to help us achieve the best treatment for your child. When your care coordinator contacts you, she will also be using this form. Your child's medication may be modified based on your input and the progress seen over a period of time.

Thanks for your cooperation!

# Prescription *Refill*

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## **IMPORTANT ADHD MEDICATION REFILL INFORMATION**

If your child has been diagnosed with ADHD, he/she may be prescribed medication treatment. When it is time for a refill of this medication, please call the clinic **at least 7 days** before the medication runs out. Medications for the treatment of ADHD are controlled substances and require that the prescription only be refilled by your child's pediatrician. By law, controlled substances can only be written prescriptions (meaning they cannot be called into the pharmacy). You may either pick up the prescription at the clinic or have it mailed to your home.

## ADHD Monitoring and Medication Effects Form

Name: \_\_\_\_\_  
Grade in School: \_\_\_\_\_

Date of Birth: \_\_\_\_\_  
School Contact: \_\_\_\_\_ &

Contact Phone #: \_\_\_\_\_  
Contact Email #: \_\_\_\_\_

|                           | Date: | Date: | Date: | Date: |
|---------------------------|-------|-------|-------|-------|
| <b>Medication Details</b> |       |       |       |       |
| Medication Name           |       |       |       |       |
| Medication Dose           |       |       |       |       |
|                           |       |       |       |       |
| <b>Behavior Effects</b>   |       |       |       |       |
| Attention to task         |       |       |       |       |
| Listening to lessons      |       |       |       |       |
| Assigned work completed   |       |       |       |       |
| Impulsivity               |       |       |       |       |
| Calling out in class      |       |       |       |       |
| Organizing work           |       |       |       |       |
| Overactivity              |       |       |       |       |
| Restless, fidgety         |       |       |       |       |
| Talkative                 |       |       |       |       |
| Aggressive                |       |       |       |       |
| Peer interaction          |       |       |       |       |

W - Worse, ND - No difference, IMP - Improved a little, XS - Improved a lot (extra special)

|   | Date: | Date: | Date: | Date: |
|---|-------|-------|-------|-------|
| <b>Side Effects</b>   |       |       |       |       |
| Comment on any changes noticed, for example:  |       |       |       |       |
| Appetite loss<br>Insomnia<br>Headaches<br>Stomachaches<br>Seems tired<br>Stares a lot<br>Irritability<br>Excessive crying<br>Motor/vocal tic<br>Nervousness<br>Sadness<br>Withdrawn |       |       |       |       |
|   |       |       |       |       |
| For Parents: Any behavior or side effect differences between mornings & afternoons when your child is home  |       |       |       |       |
| For Teachers: Any behavior or side effect differences noted between morning & afternoon classes   |       |       |       |       |

# Implementation

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- Log maintained of all phone contacts made between clinic and family
- Standardized monitoring tool used to document the children's medications, effects noted since starting the medications, and any side effects noted.
- Update phone calls encouraged every 2 weeks until appropriate medication dosage has been reached with subsequent office visits at 1 month and then every 3-6 months



# Outcome of Study

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- 36 children enrolled in study over 4 months
- Closer monitoring=timely adjustments made with medication treatment
- Better collaboration between the family and care team
- Parents were better educated about ADHD, medication dosing and timing, side effects to expect and behavioral changes

# Challenges

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- Labor intensive-additional workload to already busy nurse schedules
- “Phone tagging” with families
- Noncompliance from parents
- Unsecured website-unable to communicate with families via e-mail

# Where Are We Today?

- All nursing staff are care coordinators
- Teams work with assigned pediatricians
- Consistency with appropriate follow-up of children with ADHD who are on stimulant medication
- Modified refill procedure
- Ongoing changes



# ADHD RESOURCE CENTER

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Dedicated area in our clinic for ADHD patient monitoring

Color coded binders and folders for each physician



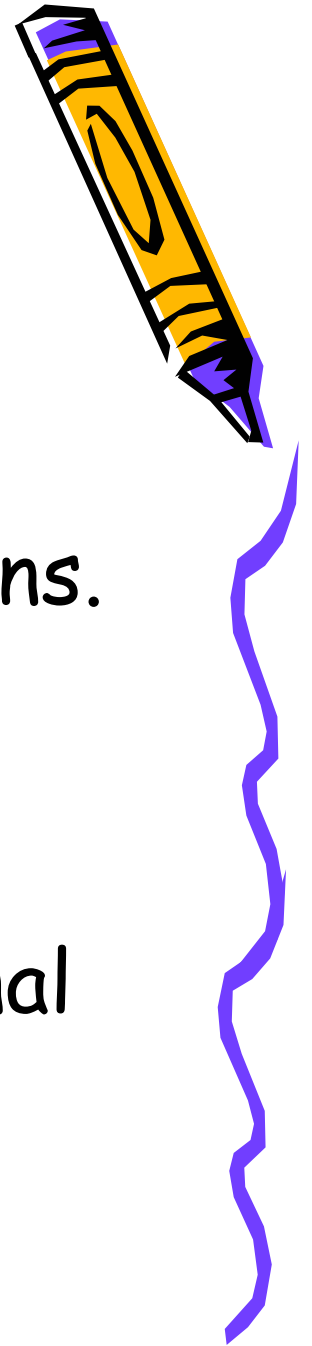
# Medical Home Capacity Building Grant

Fairview South School  
Comprehensive Health Initiative



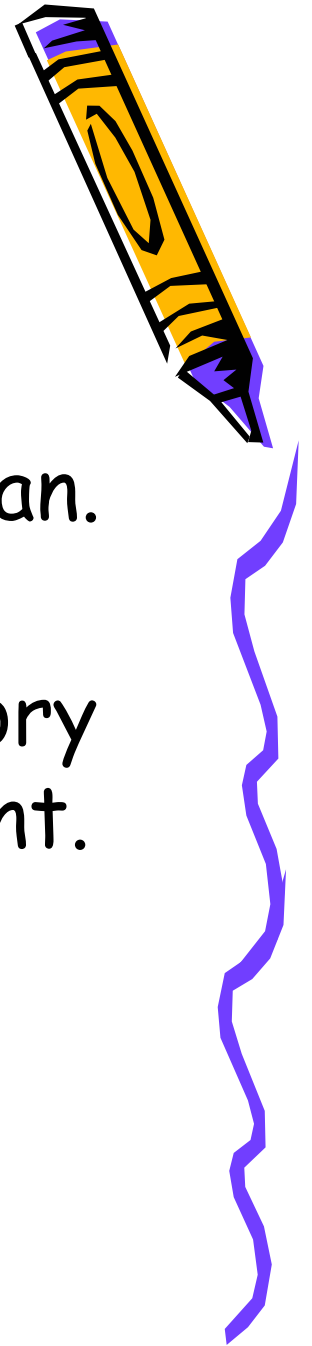
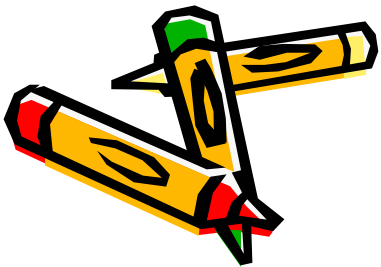
# The Medical Home Grant

- Develop better relationships with parents.
- Develop partnerships with physicians.
- Develop individual care plans that better communicate the needs of each student.
- Provide funds to support educational events for parents.



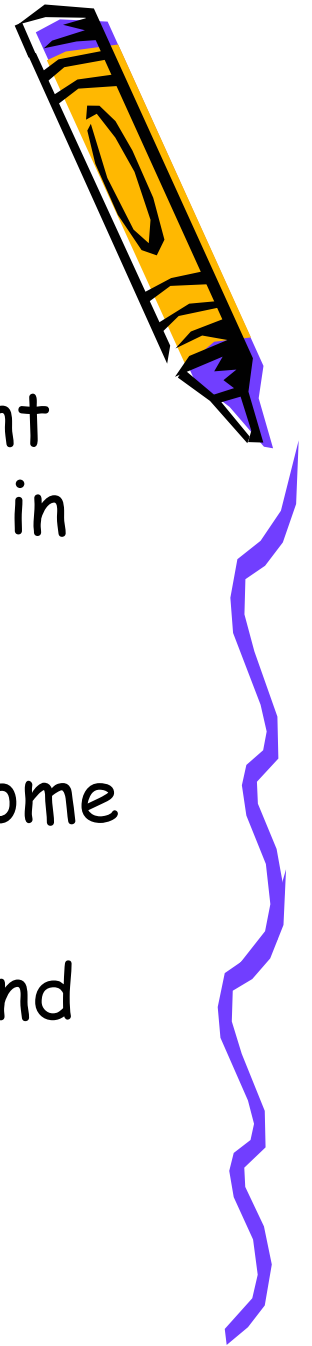
# The Role of the School Nurse

- Communication with parent/guardian.
- Individual Health Plan (IHP) that gives a comprehensive health history and meets the need of each student.
- Team work to provide consistent care.



# Communication

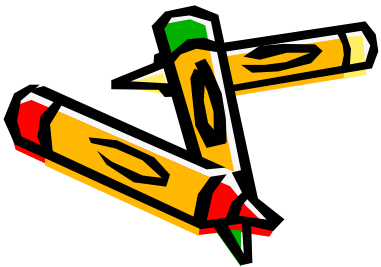
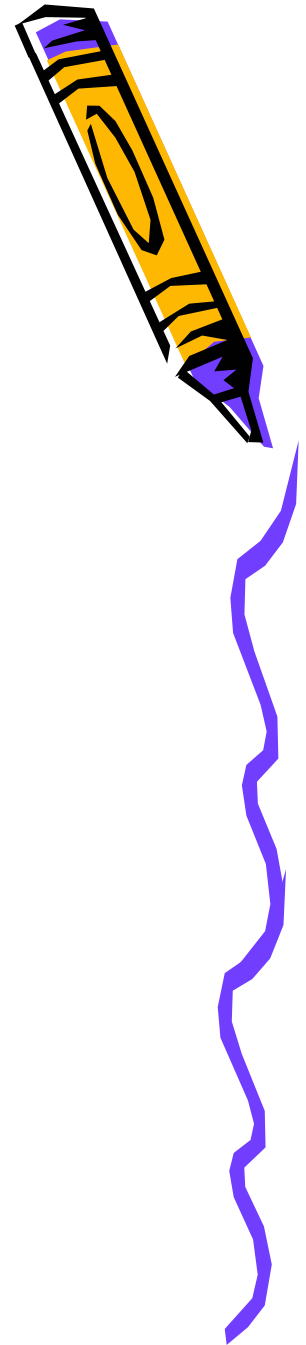
- When establishing an IHP it is important to have the parents/guardians involved in the process.
- Have the parent sign and date the IHP every year and make changes as they come up.
- Send to physician for them to look at and sign.



# Sample Face Sheet for IHP

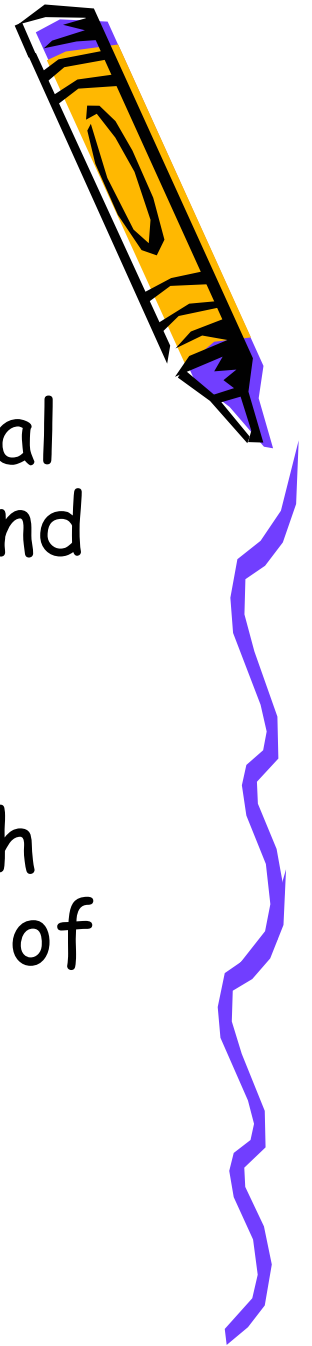
## Individual Health Plan

Name: \_\_\_\_\_ Date: \_\_\_\_\_  
Date of Birth: \_\_\_\_\_  
School: \_\_\_\_\_ Teacher: \_\_\_\_\_  
Parents: \_\_\_\_\_ Phone: Home, Cell, Work \_\_\_\_\_  
Address: \_\_\_\_\_  
Physicians: \_\_\_\_\_ Specialty \_\_\_\_\_ Phone \_\_\_\_\_  
Hospital of Choice: \_\_\_\_\_  
Allergies: \_\_\_\_\_ Type of Reaction: \_\_\_\_\_  
Medication: \_\_\_\_\_ Other: \_\_\_\_\_  
Medical Diagnoses: \_\_\_\_\_  
Surgical Procedures: \_\_\_\_\_  
Medications: \_\_\_\_\_  
At Home: \_\_\_\_\_  
At School: \_\_\_\_\_  
Nursing Diagnoses: \_\_\_\_\_



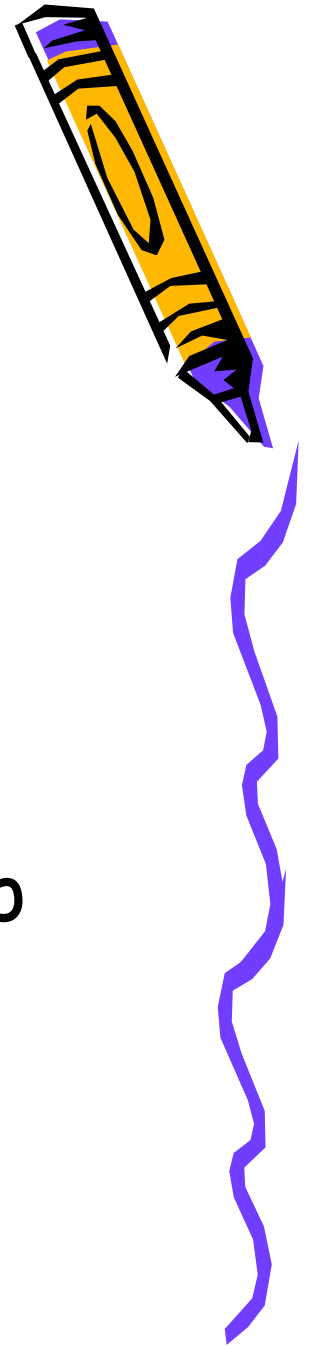
# The Great Divide

- Bridge the gap between the medical care received in a clinic/hospital and the school medical care.
- Team Effort
- School for child with special health care needs from birth to 21 years of age 7-8 hours/day.



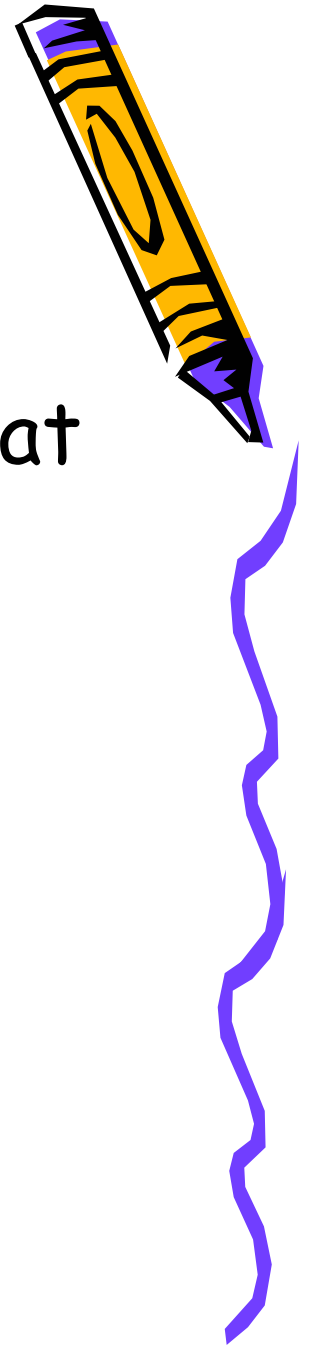
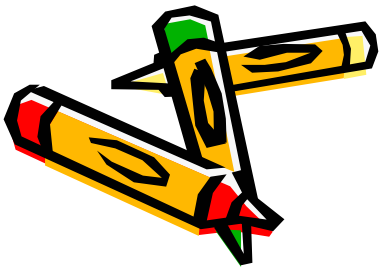
# Lessons Learned

- Important to be trustworthy and available.
- Individual health plans cannot be cookie cutter duplicates.
- Partnerships in the community help to create successful events.



# Successes

- The parent events that were held at Fairview South produced great resources for the parents.
- Partnerships have created opportunities for parents and students.
- IHP content improved.



# What's Next

- Continue to improve relationships with parents.
- Continue to improve IHP's to contain pertinent information and plan of care for students.
- Continue to advocate for special health care needs students to receive consistent health care.

