

## Helping the School Help Your Child with CdLS

*By Barbara Galyean, Master of Education in Reading, Educational Diagnostician, Licensed School Counselor*

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Parents and caregivers of school-aged children with CdLS should strive to provide and encourage strong relationships and clear communication with teachers, school nurses, administrators, and other personnel which could include support staff such as educational aides, bus drivers, cafeteria workers, custodial staff, etc. that will have contact with your child.

While much of this is developed in your child's Individualized Education Plan (IEP), sharing and clarifying this information directly with school personnel who did not attend the most recent IEP team meeting will help make them aware of their role in your child's success.

The following are some suggestions that may help:

- Arrange conferences as early in the school year as possible with everyone who will be involved with your child so that each person will know what is expected to ensure your child's safety and success. Remember, face to face meetings will help to establish the rapport necessary to insure your child's needs are met.
- Familiarize yourself with school policies and procedures and develop plans for your child during events such as fire drills, disaster drills, lock-downs, early releases, inclement weather days, as well as other emergencies that the school normally anticipates.
- Make certain all educational personnel have written copies of your child's unique needs.
- Share all distinctive traits, behaviors, learning styles, communication methods, medication side effects, feeding, toileting needs, mobility issues, and other medical concerns such as seizures and allergies.
- Provide means to enable school personnel to readily access you with their questions and concerns.
- Consider providing a list of outside sources such as the Cornelia de Lange Syndrome Foundation, personal doctors, therapists, agencies, etc. who can provide information on your child's needs.
- Provide pamphlets, magazines, articles, and any other documentation describing your child's disabilities or medical conditions. Keep in mind that not everyone is the



expert on your special child that you are.

A final reminder/disclaimer: school policies and regulations differ from state to state, and from district to district. There are some federal requirements such as those in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) that must be followed nationwide which may require you to sign a consent to access and share your child's personal information. If you have any concerns, you can always contact the CdLS Foundation for guidance.

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