



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## Special Education in the US

*By Mary T. Morse, Ph.D., Special Education Consultant, CdLS Foundation Clinical Advisory Board Member and CdLS World Federation Scientific Advisory Council*

Education is a cultural activity with schools charged to prepare children for the life they will lead in the culture in which they will live. Education can be thought of as the other side of the coin from medical and health-related issues and, as such, needs to be addressed simultaneously. How educational systems work varies from country to country, but here in the United States, there is a Federal law called "The Individuals With Disabilities Education Act," commonly known as IDEA. In turn, each state has regulations regarding how the federal law will be implemented within that state. Subsequently, each community must comply with state regulations.

There are seven major areas of the federal law and state standards: (1) **identification** of children with disabilities; (2) **referral** of the children to their local school district; (3) **evaluation** of those children who are referred; (4) **determination** of eligibility for special education services; (5) **development** of the *Individual Education Plan* (commonly known as the IEP); (6) educational services in the least restrictive environment (known as "**placement**") and (7) educational **monitoring**. I would like to address a few of these areas as related to students who have CdLS.

### Evaluation

Most (not all) evaluations conducted to establish the need for special education services include medical information and assessments by a special educator, psychologist, occupational therapist, speech/language specialist and/or physical therapist. Other educational specialists might be called in depending on the presenting areas of difficulty. Particular care must be exercised when selecting educational and psychological instruments to insure they are not discriminating owing to an emphasis upon fine motor and expressive language skills.

### Recommendation

I suggest children with CdLS also require a close examination in regard to their stamina, ability to manage sensory-motor demands, their cycles of arousal, need for structure and organization, and the ability to manage their behavior. This type of assessment may help ward off future behavioral difficulties if the initial observations are done over a series of sessions and in differing environments. It also is critical that these types of behaviors be monitored carefully and consistently once educational programming begins.

### Eligibility



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There may be some children who have the diagnosis of CdLS but do not require special education services. In this situation, the syndrome has no identified impact on the ability to profit from a regular education curriculum and no additional educational supports are needed at *the time of evaluation*. However, there are other federal laws and state regulations available to monitor the educational status of these students who may be considered "at-risk" educationally and to provide some alternative sources of support without having the student identified as having an educational disability. Even so, the great majority of children diagnosed with CdLS will be evaluated as needing special education services with some degree of therapeutic support services.

## The IEP

The IEP is a document formulated by "the Team." The term "Team" is defined as parent(s) and designated school staff. The IEP contains the student's present level of educational performance, how the disability affects involvement and progress in the general curriculum, measurable annual goals and short-term objectives. The IEP also will include related service needs, supplementary aids and supports, the extent to which the child will *not* participate in the regular classroom with non-disabled children, how goals and objectives will be measured and other very important issues related to the individual education program for that specific child - based on the evaluated needs. The IEP is a one-year plan and re-examined on a yearly basis. It is possible to revise the IEP at any time, should the parents and/or school feel there is such a need.

## Recommendation

I suggest that a long IEP is not necessarily a good IEP. A good IEP includes relevant and realistic goals and objectives, motivating and understandable activities and appropriate adaptations and supports. A *really* good IEP is a yearly plan that keeps in sight the end goal of providing the student with the skills necessary to lead the most independent, productive and satisfying life possible. In my opinion, the focus of the IEP should always remain on what skills this specific student will need in the life s/he will have when his/her school career is completed.

## Placement

Where the student goes to school and what type of program will be available is a subject of much concern to parents of children who have disabilities. I suggest the decision involves more than the debate on inclusion versus non-inclusion.

To begin, the federal law provides for a wide range of options by stating that a child with special education needs is to receive a *free appropriate public education in the least restrictive environment*. For some students the most appropriate placement may be in a special educational classroom, special school, residential facility, home-based, or pediatric

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nursing situation. Many students will be able to function in the regular classroom with supports for their entire school career. Other students may need a change in this type of placement at some point during their school years. For many, inclusion in the larger sense might mean the community of the classroom, the community of the school and the community of the town. There may be a need to teach skills in a quiet engineered environment and subsequently generalize these skills in the classroom and in the rest of the school. For many students with CdLS, inclusion may mean being accepted as a valued member of the school, but it also may mean creating a very individualized curriculum that looks very different from the other students but one that is no less justifiable.

*Inclusion does not mean the student must be in the regular classroom all the time. Nor does it mean that when the student is in the regular classroom, s/he must use the same materials or be made to look as if s/he were doing and understanding the same lessons if, indeed, they do not have that understanding. I suggest such inclusion practices are not justifiable. Finally, many students are in inclusive environments primarily for socialization purposes.*

These experiences need to be examined objectively to insure that there is real social *interaction*. Just because two or more students share a classroom or a table, does not automatically mean they are socially involved.

Perhaps the three most important points to consider are as follows: By law, placement decisions are based on the IEP - what the specific student needs educationally as a result of the disability. In turn, the IEP is based on the findings of the educational evaluation. Placement cannot be decided before the IEP. Secondly, some students with CdLS may need to move in and out of varying academic settings during the course of their school career. A singular type of placement may not be the most appropriate over the course of 18 years. Finally, each child with CdLS is an individual. One program configuration is not appropriate for all students with CdLS. "Most appropriate" and "least restrictive" are the critically important phrases to keep in mind when determining placement.