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The “Mild” Side of CdLS: The Families’ Perspective

By Lynn P. Audette, M.S.W., Family Service Coordinator, and Bruce Cleinman, M.A.

A diagnosis of "mild" CdLS may be given when individuals have some characteristics of CdLS but lack other diagnostic criteria and function at a higher level of development and independence than others with the syndrome. Many parents have commented that they feel awkward or even guilty contacting the Family Service Coordinators to ask questions about their child who may not have severe medical issues or major developmental delays. The Foundation appreciates that issues facing families whose child is mildly affected are unique but no less emotional or difficult to manage. To better understand this, several families and one adult with mild CdLS have volunteered to share their accounts.

Jordan

Although she did not have a diagnosis at birth, Jordan, who is now five, received early intervention services at eight weeks and home services until the age of three, at which time she began attending preschool for children with language delays. Michelle and Marc, Jordan’s parents feel the use of services has been critical and urge parents in similar situations to start as soon as possible.

This past year Jordan attended kindergarten in her local elementary school, starting out in a self-contained group, with integration into a typical classroom increasing over the course of the year. Her parents believe that this main-streaming helped socially acclimate Jordan and the rest of the class. In contrast to previous years, Jordan began demonstrating a surge of self-confidence and an increased willingness to take risks. Michelle states, "Jordan has done very well and loves going to school every day. Many of her academic skills, such as reading and numbers, are grade appropriate. She still has tremendous difficulty answering open ended questions, but her teachers know her well enough to make use of appropriate prompts." For years, her parents have noticed that at times Jordan can chat about complex topics with ease; other times the simplest questions appear to confuse her.

Next year Jordan will be fully integrated in "regular" first grade and will continue to receive speech, occupational and physical therapy. Outside of school, her parents encourage her to participate in various sports and dance classes. Michelle shares that it is difficult to find appropriate activities for Jordan. "She is too high-functioning for special needs programs, but as she gets older the typical extracurricular activities may prove to be too difficult. We are proud to report that she is a member of the Girl Scouts of America and loves it!"

Michelle and Marc feel that so many things are going right for Jordan, but they still worry for her future. "We are concerned that as she ages she will not be able to keep up with her typically developing classmates. If she becomes socially isolated in her current setting, we will find another [program] for her. Time will tell. However, at this point she is thriving in this



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enriched environment." Marc conclude, "Like many parents of children with CdLS, we vacillate between hope and concern for our daughter's future, but in either case we always celebrate the great joy she has brought us."

Luca

Seven-year old Luca is in a second grade Severe Communication Disorder Class with six other children. He receives speech, occupational and physical therapies and has a one-on-one aide. Luca enjoys individual attention from adults and when it is lacking, his behavior suffers. His mother, Ingrid, notes that Luca requires frequent redirection and focusing and has difficulty with transitions. This year Luca made significant improvement in both his expressive and receptive language skills. He counts with relative consistency from one to five and has begun to write his name. Ingrid feels that educators need to improve their understanding of children like Luca and that schools need to discern the best way to instruct them in math, reading and writing.

For Ingrid the most difficult and persistent issue with Luca - one that has been recurrent since he was three-years-old - is that he hits other children. Luca has to be shadowed closely in order to avoid these confrontations, but the efforts are not always successful. When it seems he has begun to modify his behavior, he resorts to it again. Ingrid shares, "He has been observed and evaluated numerous times at school over the last four years and there seem to be several reasons for it: Need for attention, lack of ability to process his thoughts and transfer them to speech, and sensory overload. Hopefully he will outgrow this behavior or learn to control it."

Luca is very active and mechanically inclined, and to ensure his safety, Ingrid has had to lock up storage sheds and cupboards containing tools, keys, cleansers and machines. He has always had a fascination with mechanical things and will explore, unscrew and manipulate them for hours when given the opportunity. Ingrid has accommodated his interests wherever possible. "For instance," his mother notes, "the stereo, remote controls, VCRs are generally accessible, although broken and lost more than usual. I've had to give up control and organization in many aspects of my life to allow Luca a sense of independence. Our house and property have been modified over the years to safely accommodate and foster his activity level, curiosity and independence."

From an early age, Luca has been included in family activities and exposed to many social environments. He has not been left with a babysitter, except in situations like the movies, where he has no interest. As a result, his older brother, Ben and younger sister, Julia, their friends and many other friends and acquaintances have learned acceptance, patience and accommodation. And Luca has been provided with opportunities to learn appropriate social behavior, inclusion, and participation in a variety of activities.

The advice Ingrid passes on to other families in a similar situation is, "Look at your child as an individual, beyond CdLS. Accept their differences and recognize the positive in those

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differences. Become aware of their strengths and build on them for the future. Provide a safe and stimulating environment at home, which will nurture their growth and development. Expose them to the world as much as possible. Be open with other children and adults about CdLS, answer questions and be willing to explain CdLS in situations where [others] may not know how or what to ask about your child."

She finished by saying, "It is always helpful and comforting to hear what other families with an individual with CdLS are experiencing and how they are handling the challenges. Until now, I have received very little information about mild CdLS in both children and adults."

Tristan

Laryssa and Devin feel that one of the biggest issues they face with seven-year-old Tristan is that he is often overlooked or misinterpreted with regard to the type and level of support services he receives. When Tristan is screened across the spectrum of his abilities (cognitive, problem solving, etc), he often tests at or slightly above his age appropriateness in some areas but well below in others. This is most evident when the schools try to place him into a regimen or program. [The programs], the Laryssa explain, "are geared for a single level rather than the broad range that Tristan falls into and end up providing little benefit to either Tristan or us as a family."

Another area of concern is Tristan's difficulty incorporating, processing and organizing information. Because of his deficits in speech, language, and short-term memory, Tristan is unable to organize and articulate his thoughts. Additionally, he must contend with noise, planning, transitions and the effects of his ADHD (Attention Deficit Hyperactivity Disorder), which can be a disruption and cause a break in his attention. In addition to ADHD, Tristan is also classified as an "explosive, inflexible child." "Because he [does not have] typical ADHD," his parents note, "but rather demonstrates ADHD tendencies and also as a result of CdLS, he has never responded to the typical ADHD medications that have been tried and we have tried them all."

Behavior affects many areas of Tristan's life, and, as he gets older, his parents find his social environment becoming less inclusive and his social situation more about his peers tolerating him or worse - ignoring him altogether. Tristan is not affected severely enough to fit in with disabled children, causing other children to overlook the fact that he can't always control his behavior. He does not get invited to many play dates or birthday parties, and is excluded in playground games at school. Tristan has not yet reached the point where he notices this, but his parents are very concerned for him emotionally.

All of these issues weigh heavily on the family, especially on their younger son, Cullen. "Most days that we are all together as a family end up being an exercise in minimizing Tristan's explosions," they share. "This usually means Cullen gets less attention, less options for what he may want to do." Tristan's behavior has become such a challenge that there is almost no part of their family life that is not strained. "For example, there are agencies for babysitters



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for children with Down Syndrome, Autism, or severe physical handicaps. But when it comes to behavioral challenges, such as Tristan's, there is nothing that we've come across."

Tristan's parents believe there are three possibilities that would help: an educational program with a staff trained for Tristan's complex behavior and learning profile; a pharmacologist more globally experienced with children such as Tristan, taking into account all the information on what makes up Tristan, and someone familiar with working outside the lines of traditional ADHD and/or behavior regimens when the more traditional means are found to be so ineffective. And, finally, a behavior program that will teach Tristan some means of dealing with his emotional challenges on his own.

His family conclude that they have hope for the upcoming school year. Tristan will attend a private therapeutic school for individuals with neurological and behavioral difficulties. He will have his own teacher and a classroom that will consist of another child with his own teacher. This setting has the potential to be more flexible and attuned to Tristan's needs. Counselors will be available and the school will introduce Tristan to a class of six other children for non-academic activities and social interaction.

Maegan

Twenty-nine-year-old Maegan was diagnosed with mild CdLS as an adult and now lives with her older sister Kathleen. Her sister was the first to suggest that she might have CdLS after discovering the Foundation website. They then went to Duke Medical Center for consultations with genetics specialists, who made the diagnosis.

"When telling others about my diagnosis," Maegan writes, "I usually say that I am mildly affected and that I have difficulties with social situations, and keeping up with things. Having [a diagnosis of] CdLS means that I have a chance to overcome obstacles. I am still having trouble adapting to work. Luckily, I have Vocational Rehabilitation and a job coach to help me through."

Maegan, who is able to write and speak clearly, graduated from a regular high school in 1993. She even attended college for a time. Like many individuals with mild CdLS, she is shy, but with time can fit into different social situations. Maegan likes to draw and work out at the YMCA. She also attends group sessions to help overcome her social anxiety. "I also love to listen to music and explore the Internet."

Maegan states, "I think that a common misperception people have about me when they learn I have mild CdLS is that I am not capable of doing things for myself. I'd like people to understand that I am a great person inside. I just need to help with some things: social, vocational, and planning skills."

It is apparent from contact with the individuals in this article that there are formidable challenges for persons having mild CdLS and their families. These include: promoting social

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integration with and acceptance by peers, the need for effective behavioral programs, fostering emotional and interpersonal functioning, providing a normalized environment to encourage independence and securing appropriate services and programs to meet the needs of individuals and families.

Assistance in meeting these challenges can be found through the Family Services Coordinators and the professionals on the International SAC (Scientific Advisory Council). It is further evidenced from talking with families that there is a lack of information available at this time about mild CdLS. Until more information is forthcoming, it is the Foundation's hope that this gap can be bridged in part by appropriately matching families with each other for mutual support, sharing and information. If you are interested in being matched up with another family please contact Lynn at the Foundation.

Thank you to the Fischers, Calhouns, Barones and Maegan for their kind contributions to this article.