CANADIAN CDLS FOUNDATION

CdLS
Family Welcome Package

The Perfect Fit

Resources, tools and considerations for learning & education for individuals with Cornelia de Lange Syndrome (CdLS)…

Dedicated to all families impacted by CdLS and their educators who are committed to creating a caring, compassionate and sale learning environment and gaining expertise as a life long learner. Extreme gratitude for our colleagues at the US CdLS Foundation and their education advisors who allow us to share their knowledge and expertise.

By Canadian CdLS Foundation

Content in this Education Resource Tool-Kit has been collated with permission from the authors with a significant amount of knowledge shared by the US CdLS Foundation and their education advisors with decades of experience. Additional information from various Canadian special education references and school board resources have been referenced. This Tool-Kit is continually evolving and new content and tools are being added. We recognize that knowledge is forever advancing and changing and hence we know this will need constant updating and work to remain current. Appreciate progress over perfection.

Canadian CdLS Foundation
5 Copeland St. #1316
East York, ON.
Canada

www.canadiancdlsfoundation.com

Prologue

Individuals impacted by CdLS encompass a broad spectrum of the level of impact on development, cognition and learning. This tool has been created to support parents, educators and support staff as a resource tool.

Local resources should be consulted as well as local experts to determine the type of education, school, the type of learner and the individuals needs of the person with CdLS to create an opportunity to create a lifetime of learning. Individuals with CdLS demonstrate their ability to acquire new knowledge and skills throughout their life despite the severity of impact of CdLS.

Chapter 1 - How to Develop a Child's Best Advocate

By Darrell Cookman, condensed from a workshop presented at the CdLS USA Foundation's 21st International Conference by keynote speaker, Patty McGill Smith

Advocacy should "start at the grassroots, in your yard, at your own house, with your own child." The most reasonable choice for a child's best advocate is, of course, her or his parent(s)/caregiver. The challenge is how to get . . . to the point of successful advocacy. In the first year, "you're not really able to be your own advocate. You're too beat up yourself, you're too worried, you're too confused, and you're too . . . everything . . . its really hard.

"The answer to becoming a good advocate is education, it's knowledge, it's knowing what you're talking about. And then it's learning to know how to present knowledge, how to make your point, how to let people know what your needs are, not to be intimidated.

Years ago, a movement known as "Normalization . . . a body of ideas and thoughts . . . A complete way to approach taking care of people with disabilities" was created. It encompassed concepts such as age appropriateness, considering a developmental model, and the evaluating the degree of risk and experience to which a person should be exposed.

"I've always been so taken that parents of kids who are disabled, they don't want to let them fall down. They want to stop them from ever getting hurt . . . And I'm not advocating that you get your kid hurt, but on the other hand, how did you learn some of the things you learned? You learned by experience, and so if you keep them so encapsulated that they can't try stuff, then they can't learn, at least from that experience. And so I urge all of you (to) give them the opportunity, however you go about it, to experience as much as they possibly can . . . That's how they learn, it's part of discipline too . . . Sometimes we encapsulate children so much that they don't even have the opportunity to learn."

Basic Rules for Successful Advocacy

1. Develop for yourself a formula for success. Form a business plan, work from your strengths, make it personal.
2. Learn to say "no". Don't get spread too thin once you become good at this.
3. Have confidence in yourself. An advanced degree or training is not necessary.
4. Refuse to be intimidated "You are the expert for your child. You know more about what's happening with your child than anybody else."
5. Know your rights "What are the rights for your child? The right to education is a human right. It is a human right and it's in the Human Rights Code. Children have the right to what everybody else has . . . You're going to find out that it might be difficult to get those rights enforced and so learn what they are."

On December 13, 2006, the United Nations General Assembly formally adopted the Convention on the Rights of Persons with Disabilities (CRPD). The purpose of the Convention is to promote, defend, and reinforce the human rights of all persons with disabilities. Ratified by Canada in 2010, the CRPD is a tool that helps communities and governments understand why and how the rights of people with disabilities aren't being realized. It provides a framework that articulates the conditions needed to make rights a reality. While the CRPD does not establish any new rights for people with disabilities, it introduces new concepts that are necessary for the realization of a right. The CRPD provides an aspirational direction to guide our efforts to build an inclusive and accessible Canada. The CRPD can make a meaningful difference in lives of people with disabilities and their families in Canada and around the word.

Article 24 – Inclusive Education

Article 24 of the CRPD prohibits discrimination against children with disabilities and mandates the right to inclusive education. This provision is focused on removing barriers to participation in typical classrooms in public schools and thus promotes inclusion in the community and society as a whole. State parties (countries) are specifically charged with the

obligation to ensure access to inclusive general education with non- disabled peers. This is the first time this right to inclusive education has been explicitly articulated in international human rights law. The Parliament of Canada and each Canadian province have ratified the Convention and thus accepted this as law in our country.

While progress has been made toward ensuring access to inclusive education, Canada is still not fully in compliance with Article 24. There are still obstacles to be removed and supports to be developed and funded. Each province and territory in Canada has work to do to fulfill the promise of the Convention. Inclusive Education Canada is working to meet this challenge.

6. Communicate effectively. Develop your own style. Speak up and speak out. Share your success; learn from each other. "If you ever get denied anything, you remember that Patty Smith said you appeal, you appeal, you appeal. You never accept anything without appeal. . . Appeals are won at the level of 50% on the first appeal."

A few keys to success:
* Tenacity
* Know your rights
* Be resourceful, innovative
* Follow your own instincts
* Learn to articulate your needs
* Be willing to "Rock the Boat"
* Avoid haste
* Never lie, exaggerate
* Convey courage
* Expect unexpected
* Keep good records

"Get the door open for one, get the door open for two, and the first thing you know, you've got the door open for a whole bunch of people." Systems Advocacy If you want to change something at the local, provincial, or federal level, every one of you can articulate your story and you can make that change happen . . . "Not that everybody is going to do that. I don't want you to think that. I want you to just keep yourself open to the possibility."

Chapter 2 - Your Child's Assessments and Evaluations for and at School

Contributions from Janette Peracchio, M.Ed.

When a child with Cornelia de Lange Syndrome (CdLS) is first born, there are many tests and evaluations done at the hospital to determine their health status, and if they need special health care. Children with CdLS may be diagnosed within a few days of birth or much later in their childhood, and in very mild cases later in adulthood. However, most qualify to receive Early Intervention (birth to school age) services in their home or a local rehabilitation setting. These are provincial programs that help educate parents and their babies who are at risk for needing special therapies and education before they start school. At age four, the child and family transition to public education in the public or catholic school boards where the family lives takes over and provides the child with a free education under the Education Act. In most provinces individuals on an IEP can attend high school until age 21. Before a child can receive special education and related services from the school district for the first time, an individual evaluation of the child must be conducted to see if the child has a disability and is eligible for special education. All school boards must set up an identification, placement and review committee (IPRC). Parental consent must be obtained in writing before this evaluation can be conducted. Regulation 181/98 of the Education Act sets out how IPRCs identify and place students (below) in special education programs. Names and titles may vary across programs in different provinces, however, they are quite similar in every school board. For students whose needs cannot be met entirely in the regular classroom, a range of placement options is available, including a:

1.Regular class with indirect support where the student is placed in a regular class for the entire day, and the teacher receives specialized consultative service

2. Regular class with resource assistance where the student is placed in a regular class for most or all of the day and receives specialized instruction, individually or in a small group, within the regular classroom from a qualified special education teacher

3. Regular class with withdrawal assistance where the student is placed in a regular class and receives instruction outside the classroom, for less than 50% of the school day, from a qualified special education teacher

4. Special education class with partial integration where the student is placed in a special education class for at least 50% of the school day and is integrated with a regular class for at least one instructional period daily

5. Full-time special education class for the entire school day

The evaluation is done to gather information that will help determine the child's educational needs and to guide decision making about appropriate educational programming for the child. The evaluation must use a variety of assessment tools and strategies to gather relevant functional, developmental, and academic information about the child, including information provided by the parent. When conducting an initial evaluation, it's important to examine all areas of a child's functioning:

- Health
- Vision and hearing
- Social and emotional status
- General cognition and learning style
- Academic performance
- Communicative skills
- Fine and gross motor abilities
- Strengths, preferences and needs.

The school system must ensure that the evaluation is sufficiently comprehensive to identify all of the child's special education and related service needs (therapies— occupational therapy, physical therapy, speech and language, etc.) Assessments should occur across a variety of natural environments (home, school, community). The evaluation must use a variety of assessment tools and strategies. It is inappropriate and unacceptable to base any eligibility decision upon the results of only one procedure. Tests alone will not give a comprehensive picture of how a child performs or what he/she knows or does not know. Only by collecting data through a variety of formal and informal approaches (e.g., observations, interviews with parents and former teachers, using teacher constructed tests, curriculum-based assessment, and so on) and from a variety of sources (specialists and the child) can an adequate picture be obtained of the child's strengths and weaknesses. Schools should use technically sound instruments and processes during an evaluation. Technically sound instruments generally refer to formal assessments that have been shown, through research, to be valid and reliable. Technically sound processes require that assessments and other evaluation materials be:

- Administered by trained and knowledgeable personnel;

- Administered in accordance with any instructions provided by the producer of the assessments; and

- Used for the purposes for which the assessments or measures are valid and reliable.

Another important component in evaluation is to ensure that assessment tools are not discriminatory on a racial or cultural basis. Evaluation must also be conducted in the child's typical, accustomed mode of communication (unless it is clearly not feasible todo so) and in a form that will yield accurate information about what the child knows and can do academically, developmentally and functionally. If the child has limited English proficiency, materials and procedures used to assess the child must be selected and administered to ensure

that they measure the extent to which the child has a disability and needs special education, rather than measuring the child's English language skills. This provision in the law is meant to protect children of different racial, cultural, or language backgrounds from misdiagnosis. If a child speaks a language other than English or has limited English proficiency, he/she may not understand directions or words on tests and may be unable to answer correctly. As a result, a child may mistakenly appear to be a slow learner or to have a hearing or communication problem. If parents of a child with a disability
disagree with the results of the child's evaluation done by the school board, they have the right to appeal the decision. This appeal has to be done in writing to the board secretary. Each province outlines this process in detail on their provincial education websites. The results may also be presented as evidence at a hearing regarding your child. Re-evaluations can also occur more frequently if conditions warrant, or if parents or the child's teacher requests a reevaluation. Informed parental consent is also necessary for reevaluations to be conducted. Before the reevaluation study can begin, parents receive a written notice that describes the tests, who will perform them and procedures to be used with the child. Once the evaluation is completed, the planning and placement team will meet to interpret the evaluation data. Parents then receive a copy of the evaluation report for your records.

Psycho-Educational Testing Approaches for Children with CdLS

By Shelly Champion, M.Ed, Co-Chair - US CdLS Foundation Professional Development Committee Used with permission from the US CdLS Foundation

Before a child can receive special education and related services from the school district for the first time, an individual evaluation of the child must be conducted to see if the child has a disability and is eligible for special education as defined by the Education Act. Parental consent must be obtained in writing before this evaluation can be conducted. The evaluation is done to gather information that will determine the child's educational needs and guide decision-making about appropriate educational programming for the child. The tests and assessments must be valid and reliable, administered by trained examiners and given in the child's primary mode of communication. After the evaluation the school will provide you with a copy of the evaluation report. Students with Cornelia de Lange Syndrome (CdLS) demonstrate a wide range of physical and cognitive manifestations. There are many assessments to choose from and which to use depends on the child's abilities and needs. There are a few things to consider: the child's language ability and mode of communication, the child's physical abilities, and temperament.

The evaluation must assess all areas related to the child's disability, including:

- Health
- Vision and hearing
- Social and emotional status
- General intelligence and learning style

- Communication abilities
- Fine and gross motor abilities
- Strengths, preferences and needs

Tests alone will not give a comprehensive picture of how a child performs or what he/she knows or does not know. Only by collecting data through a variety of formal and informal approaches (observations, interviews with teachers and family) can an adequate picture be obtained of the child's weaknesses and strengths. A comprehensive assessment is one that includes tests of intelligence, academic achievement and adaptive behaviour (daily living skills, communication skill, and social skills). The evaluation should identify the child's needs in other areas such as speech and language, occupational and physical therapy, and need for assistive technology or transition services. Intelligence testing can tell you how your child is functioning cognitively. Intelligence tests are important in establishing realistic expectations of your child's abilities measure different skills, including:

- Verbal reasoning and vocabulary: thinking with words
- Fluid reasoning: using language to solve unfamiliar problems
- Visual-spatial and visual-motor skills; thinking with pictures, designs, and hands
- Short-term and working memory

• Long term memory and retrieval: recalling factual information and retrieving it from memory • Processing speed: making small decisions quickly with pencil in hand

Examples of test of cognition are:

• Wechsler Intelligence Test for Children – Firth Edition (WISC-V) for ages 6 through 16. The WISC-V is a standardized test that assesses verbal and perceptual (i.e. non-verbal) reasoning ability using a variety of tasks, including answering questions, defining words, and working with blocks and pictures. Also assesses working memory through tasks.

- Wechsler Preschool and Primary Scale (WPPSI) for ages 2.6 through 7.7

- Wechsler Adult Intelligence Test for ages 16 and up

Intelligence tests should allow the child to demonstrate their abilities and not be penalized for their disabilities. Such intelligence tests may omit expressive language and/or visual motor skills. The WISC-IV depends on a child's verbal ability. If a child has weak oral language skills, the test used will not require expressive language skills.

Sample Psycho-educational Assessment found in appendix 1.

Chapter 3 - Educational Placement Options and School Supports

All children with CdLS are entitled to a free appropriate public education. An education that is:

- designed to meet the unique educational needs of that one student;
- addresses both academic needs and functional needs;
- provides access to the general curriculum to meet the challenging expectations established for all children (that is, it meets the approximate grade-level standards of the provincial educational standards, to the extent that this is appropriate;
- is provided in accordance with the Individualized Education Program (IEP);
- is reasonably calculated to enable the child to receive educational benefits.

Options for educational placement can be as varied as there are children with CdLS.

Chapter 4 - Guidelines for Evaluating a Pre-School Program for Children with CdLS

by Mary Morse, Ph.D.

Assessment

What types of assessments is the school going to use? What modifications to the testing procedures will be necessary -- especially if the child has no language (which means she needs non-language-based testing)? What help do the assessors, themselves, feel they need in testing?

Examining the Physical Environment

What does the room look like? Would you like to spend the day in the room? Is the room cheerful but not overwhelming? Is it loud and noisy or calm and welcoming? Is the classroom, playground, and bathroom equipment safe (especially if the child is as small as many other children with CdLS)? Are there a variety of play stations as, for example, arts/crafts,

puzzle-reading area, kitchen corner and other make-believe areas. Are the materials organized so that a child has a sense of knowing where to go to find certain types of toys? If the child mouths objects, what provisions can be made for keeping very small ones, which she might swallow, out of her reach rather than yelling at her? Is there somewhere she can go when she needs a break from the other children -- a quiet, secure, safe place? Do the children look happy and calm to you? Is the teacher relaxed? Is there sufficient staff for the number of children? If the program is only for children who have disabilities, then more staff will be needed. If she is the only child with disabilities, will she have a personal aide? You could ask the teacher what kind of help she feels she needs to better understand a child who has CdLS.

Curriculum

What activities, exactly, do the children engage in? Are the activities appropriate for the age and developmental level of the child? For instance, age three is the time to play, to engage in make-believe, to be creative in one's own way with paint, magic markers and other arts/crafts materials. It is the time to learn how to play with others. It is not a time for serious counting and learning the alphabet or drawing within lines. These kinds of cognitive tasks are developed in other ways in early schooling. Indeed, preschool is primarily to develop personally and socially through:

- accomplishing successful separation developing a sense of independence and self- confidence
- increasing impulse control and ability to accept limits
- increasing level of attention and involvement in activities (this is more easily accomplished when we start with the child's interests and shape them)
- improving ability to make transitions and follow routines
- developing increased self-help skills increasing positive interactions with peers
- developing gross motor skills, body awareness (proprioception)
- developing fine motor and perceptual skills
- developing cognitive skills

If the child is similar to other children with CdLS with whom I work, certain activities will be very difficult for her: for example, sitting and listening to a story if she does not understand language. Sometimes the children start to engage in all kinds of distracting activities, because they do not understand the stories and the experience has no meaning to them. If this is the situation with the child, what adaptations is the teacher willing to make so a problem will not occur?

Another common problem is the tendency to think all children can move from activity to activity at the same pace. It may be necessary to identify which activities are most important for the child to engage in and which ones are not necessary, at least initially. Rushing the children from one activity to another has been quite stressful for children with CdLS. On the other hand, allowing the majority of free time to be unstructured has also been a problem since many of the children do not know how to productively occupy themselves. So there really needs to be structure and organization in the sequence of activities, help in knowing what activities to participate in, teaching so she will know how to do the activity, time to experiment with the activity after the teaching, and time to have a break from all the effort. What other adaptations will be necessary to accommodate for this child? How will the staff identify these adaptations? I am particularly concerned with adaptations which might be necessary if the child has no language. She will need a method to express what she wants and the staff will need a way to tell her what is going to occur.

What therapies will she receive?
Will the therapies be integrated within the activities of her school day? Social Interaction
Will the program include children without disabilities who can be role models for the children who do have disabilities?
How will the staff facilitate interaction between the children?
My own philosophy is to plan ahead (be proactive) rather than wait for a problem to occur and then have to fix it (reactive).
Those programs to whom I consult which have children with CdLS have, by and large, been pro-active and the children are doing well. The staff members have been willing to try new ideas and I, in turn, have learned from them.

Chapter 5 - Choosing an Educational Placement for Your Child

Shelly Champion, M.Ed.; US CdLS Foundation Professional Development Committee, cochair

Regardless of a person's mental or physical limitations, all children with Cornelia de Lange Syndrome (CdLS) have the ability to learn. The goal of education should be to educate the child to develop their full potential. The federal law known as Individuals with Disabilities Education Act (IDEA) mandates that every child is entitled to a Free Appropriate Public Education (FAPE) including an Individual Educational Program (IEP) and in the Least Restrictive Environment (LRE). There are many options available for a child's education. Deciding what is best for your child can be confusing and overwhelming, but with a few suggestions, it is manageable. The first step is to have the school system evaluate your child - determine the areas of strengths and challenges (what is their best learning style, how to handle behaviours if present, and determine the type of environment that is best for him or her). At the IEP meeting you will talk about your child's strengths and challenges, set measurable goals, look for a setting that fits and that will help your child achieve his/her goals whether it involves communication, academics, social skills, physical skills, getting ready for college, post graduate study, and /or learning work skills. Once evaluations have been completed and the education team meets, options for the child's education will be discussed. There are many options available:

1. Inclusion or mainstream class is a placement where your child will be in a regular education class with their age peers. Your child will have a regular education teacher and a special education teacher whose job it is to adjust the curriculum to your child's abilities.

2. A resource room is a setting where a child receives instruction outside of the regular education setting with a special education teacher in a small group setting using techniques that are effective for your child. The student is usually with his/her regular education peers for most or some of the day.

3. In a self-contained classroom your child is removed from the general school population for all academic subjects and works in a controlled environment with a special education teacher. Self-contained classes provide structure, routine, and appropriate expectations. Students work at their own level.
4. While some self-contained classrooms are in the local public school, others are considered out-of-district when the school is outside of your neighbourhood. Out-of-district placements do provide specialized instruction to address special learning or behavioural needs. These schools provide a high degree of structure, routine, and consistency throughout the school day. However, they remove any possibility of interacting with regular education students and are costly to school districts.

5. Sometimes a private setting is considered and is paid for by the school district if there is no other placement in which the child will receive an education designed to meet any unique educational needs. Some parents may opt to pay for a private school.

6. Some children with CdLS require a residential setting in which they live at the school they are attending and receive around the clock care. For some children with severe medical needs, their education may be in a hospital setting.

Deciding which is right for your child is based on his/her individualized needs. Ask yourself what kind of setting your child learns best in. Parents have a lot of input into their child's education since they know if they respond best to rigid schedules and strict discipline or if they blossom with hands-on projects and move at their own pace. You know whether your child has friends that they want to socialize with or whether the mainstream has been unfriendly or dangerous. Does your child enjoy different teachers or prefer the consistency of the same teacher? Research shows that children learn best in the LRE. For some that would be close to home with their general education peers. For others it might be a self-contained setting.

The following are some tips in searching for an appropriate school:

Look at the overall environment. Is the school doing what they say they will? If they are practicing inclusion, are the supports in place for the child in the classroom with the necessary curriculum adjustments. If your child needs a quiet

space to calm down, will it be provided, and how? Do teachers use a variety of instructional methods? Are there school-wide projects that can include the needs of your child? Ask about the principals background and experience with special education (they are largely responsible for the special education programs in the school) and ask the same about the staff, teachers and paraprofessionals. If your child needs close supervision, ask who will be responsible. How are teachers trained and tracked? If your child has both a regular education teacher and a special education teacher, how do they communicate? Do they team teach or is your child taken out of the classroom? Do they meet often to discuss your child's progress? Ask your child's teacher about assessment, instruction, and evaluation regarding your child's learning needs. What are the assessments and what do they do with the results? Are the results used to determine instructional needs? Are evaluations informative and ongoing or just at the end of units? It is important for family and school staff to be working together. Does the school have open communication between the family and school outside report card times, either through a notebook, phone calls, email or text? Does the school staff ask for input from the family? Most importantly, does the school feel inviting to you and your child and do you see a happy developing child come home from school every day? In conclusion, you need to advocate for your child. You know him/her best and can gauge what setting would be the most productive, beneficial and stimulating place for your child to learn in. Not every school can provide services equally, which is why it's important to interview more than one placement. Public and private schools both have services to offer. There is not one best solution. The placement should be monitored closely to determine what is or isn't working. Remember that your child's placement is not permanent. If the placement is not working, your child's behaviour is increasing, or he/she is not making progress, you can request that the educational team meet and revaluate the placement. All children are constantly developing: what placement works this year may not be beneficial the next year.

Chapter 6 - Back to School Basics

By Janette Peracchio, M.Ed, US CdLS Foundation Family Service Coordinator

With the new school year right around the corner, it's time to prepare your child for the transition back to the classroom. Parents and children may feel both joy and dread about starting a new academic year, and there are ways to make the return to school less stressful. Start transitioning your child back to school towards the end of summer break by talking about school and looking at pictures of her classroom and friends from the previous year. Let her help choose a book bag, school clothes and supplies. Begin wake-up and bedtime routines a few weeks before school starts. Avoid any negative conversations about school or the staff, and don't talk about missing your child when she is in school. Focus on the positive school experiences that she enjoys.

To prepare teachers and therapists, especially if they are new to your child, it's important to have a meeting prior to the first day of school. Be sure to provide information about CdLS and let them know about the Foundation and its resources.

Ideally, this introduction would've taken place at the end of the previous school year or during summer school (if your child attends), allowing the professionals to see your child in class and become familiar with her level of functioning. The new teacher and therapists should receive reports from the previous year's staff that shares your child's preferences and skills.

It's also helpful if you visit the classroom a day or two before school starts in order to bring any special equipment or supplies your child needs in the classroom. Be sure to call the school office to make an appointment with the teacher at a convenient time. Relationship building begins right away, and it's helpful if the teacher knows you want to be an active participant in your child's success at school.

Parents also need time to prepare for back to school. Choosing supplemental child care and shopping for supplies and clothes takes time, but these tasks are important for a smooth start to the new school year. Purchase a notebook to keep a written record of all phone calls and correspondence with the school. Once school starts, ask questions about anything that you don't understand. Let staff know when you think they're doing a good job and when you feel that things aren't going well. Remember, although the teachers are the ones teaching, they're also learning a great deal from you and your child. It's rare for teachers to have a student with CdLS during their careers, so you'll be an important resource to them.

Be an equal, contributing member of the educational team that works with your child. Attend team meetings and open houses, visit the classroom, and participate in special activities. Know what the teacher is doing at school so you can reinforce the skills at home. Find opportunities for your child to continue to learn in school-like settings during school breaks. Sports, music, art, crafts, camps, parks, and community programs can help you and your child discover new interests. Most important, remember that if your child has a positive attitude towards school, success follows.

Chapter 7 - Helping Children with CdLS Stay Focused in School

answered by Mary Morse, Ph.D.

Question. My child's teacher reports that he has difficulty moving from one activity to another. She also says my child is easily distracted and often becomes anxious during school activities. Do you have any suggestions?

Answer. By and large, attention is related to the ability to manage states of arousal which, in turn, is both a neurological and a motivational function. Neurologically, a child needs to be prepared to receive, organize and interpret incoming sensory information.

To do this involves,

(a) the ability to withdraw attention from some other event in the environment (i.e., preservative behaviours),
(b) knowing what to attend to and,
(c) inhibiting competing events occurring at the same time. Simultaneously, no one can sustain attention if they do not find the activity motivating.

When children perceive the activity as pleasurable and interesting, they find the activity reinforcing. Young children must have immediate payoff. Concurrently, when children become anxious, they engage in more stereotypic behaviours. In my experience, children with CdLS easily become anxious. Some may withdraw into their own personal world, while others demonstrate a range of frenetic motor movements running, twirling, sweeping items off shelves, etc. From an educational perspective, children seem to do better when they can anticipate what is to occur and when they have some type of communication system. They also seem more settled when they are not rushed and when they have a sense of competency as related to the task. I suggest controlling the type, intensity and duration of sensory information so the demands of the task are clear especially for new sensory motor tasks. When children feel overwhelmed, the tendency is to revert to behaviours that provide comfort; such as twirling or staring at their hands. I also suggest providing sensory input gradually to avoid over stimulation, recognizing that sensory input may be cumulative. An exaggerated response may be a result of the whole day's input and not just a single touch or type of sensory experience. Ideas to Assist School Staff I am in hopes that some of the following ideas will be of help to you and your son's teacher: Your child may benefit from "calming" activities that many occupational therapists (not all) are trained in. I have seen tremendous changes in hyperactive type behaviour when these calming techniques are used at regular intervals throughout the day. Indeed, the techniques are referred to as a "sensory diet." It may be helpful for your child to have an area to go to for “sensory break." One of the children with CdLS I see regularly has a small blocked off area in the classroom. This little den has no visual stimulation (all grey), blocks out a lot of classroom noise, has many soft pillows, and a weighted vest is available. When he feels anxious, he goes into his little area. We know the level of his anxiety depending on whether he reaches for the weighted vest as a request to place it over him or if he just settles into the pillows. The technique does not work for all children, but this child has learned to recognize when he has had enough and knows what he can do about it. Sometimes he needs encouragement to come out but, as time goes by, he uses his den more and more appropriately. This technique seemed preferable to running frantically about the room and banging his head on the floor. The area was never used as punishment. Schedule Systems Can Help Schedule systems work extremely well with children who may have a difficult time perceiving routine and/or those who become stressed when the routine is changed and/or those who may have difficulty understanding the full range of language used to describe what is going to occur. There are many different schedule systems, the choice of which depends on the child's strongest level of receptive communication (not developing level), i.e., objects, object symbols, photographs, drawings and/or printed words understanding.

The system is most effective if it is

(a) physically accessible to the child but in a quiet area,
(b) when teacher and child review what activities will be done during the day each morning (scripting the name label of each activity) and
(c) literally showing the child if the schedule changes via words and changing the object/ object symbol or photograph sequence.

Introduce new experiences carefully. Choose activities and materials based on other familiar activities and materials. Teaching a new motor pattern by using familiar materials or using new materials while enjoying a familiar motor pattern helps to make new experiences less scary.

Organize Activities in Sequence. Organize activities so your child literally can see what needs to be done and in what order. For example: In a pasting activity there are three major steps selecting the material to be pasted, getting the paste onto the material and placing the pasted material onto the designated background. Create an activity sequence setup in a defined area (i.e., non-patterned place mat or work tray) with a clear sequence of steps, a clear beginning and ending, and motor-friendly materials. The adult facilitator uses his/her own hand in a slow, theatrical manner to demonstrate how to do the activity. It is especially helpful when the demonstration shows the rhythmical aspect of the activity and the vocal language corresponds to the motor movements. For example, the adult might perform the individual motor movements and simultaneously say "pick, dip, paste," then pause to allow your child time to process what he saw and heard. The adult repeats the activity several times and then pauses at the beginning with his hand held in such a manner to suggest that the child join in. If he feels the need to ride the adult's hand to understand the motor acts, I suggest allowing it for several rounds, keeping the language and the movement to the same rhythm. After several rounds, say "(Name of child) do" and use your own hand to point to the steps. Gradually fade all assistance. I have observed that activities such as circle are sometimes difficult. If that is so for your child, he may find that listening to action songs, watching others, maintaining position in space and having his hands moved to be overwhelming. In this situation, it might be better to allow him to get used to the routine and the activity without active motor participation. Later, assist him with the motor movements simplifying them initially. Such assistance might be more effective if the adult sits behind your child and allows him to ride the adult's hand. This hand-under-hand technique will allow him to feel the natural motion without having the tactile interference of someone holding onto his hand. Additionally, your child can monitor his own state of arousal by keeping his hands on the adult or removing his hands.

Chapter 8 - Smooth Transitions at School

By Janette Peracchio, M.Ed., US CdLS Foundation Family Service Coordinator

Like all students who attend school, children with disabilities go through major transitions. Knowing what the issues are as you face each of these transitions with your child help you become a strong advocate. Remember that most teachers and therapists have never worked with a child who has CdLS. As your child's advocate, you must teach others about the syndrome and about your child's needs. Education planning for children with CdLS requires a great deal of thought, planning, evaluating, researching, meeting, discussing—and sometimes arguing—with the school district's planning teams to ensure your child has an Individualized Education Plan (IEP) and access to the curriculum that is mandated by federal law. Age four is an important milestone. With that birthday comes a transition from Early Intervention (EI) to attending a local school. At least three months before your child's fourth birthday, contact the school's special education department. Your child will go through an evaluation to determine eligibility for special education preschool. The evaluation should be fun for your child; the results may be traumatic for you. It is not easy to hear about deficits your child may have and therapies he or she needs. When your child turns five, it is time to transition to kindergarten. This may mean going from a partial day to a full day, and/or changing schools, therapists and teachers. You will be part of the Individual Education Plan (IEP) team. An IEP is a plan created especially for your child and includes what therapies and accommodations will be made for him or her. The team decides if the child is ready for kindergarten, which class is appropriate and why. This is a big, important transition, but don't feel bad if the team recommends delaying kindergarten for a year You can ask to see the different classrooms, meet teachers and think about whether your child would fit into the environment. If out-of-

district placement is offered, or if you would like to investigate other programs, visit those classrooms as well. During the elementary school years, make sure that the elements of the IEP have been established to meet all of your child's needs. This includes continued growth each year with new goals and objectives; a communication system that your child and the team use consistently; adequate busing needs;; a educational assistant (if needed); and a behaviour plan. Transitioning to the higher grades can be challenging. The child's peers are getting bigger and more independent. Even the buildings are larger. With the move to high school comes notable changes in students' roles and interpersonal relationships. Adults should help students with special needs feel included in class and all extracurricular activities that are of interest to the student. Again, as your child's best advocate you must be his or her voice. Keep clothing, haircuts and leisure time activities age-appropriate. Bibs and Big Bird should not travel to ninth grade in a backpack. Ask yourself, "What are his peers doing?" The answer, most likely, is listening to music and spending time with friends. You have to create those opportunities for your child. Successful transitions are marked by students who feel like they belong and that people care about them and know their names. The final transition from school to adulthood takes many years to work on with a transition specialist at the high school or your province's Developmental Disabilities Agency. Ideally, the foundation for that journey is built throughout your child's high school years. It is never too early to begin planning and dreaming about your child as an adult.

Some families have chosen to homeschool their children and in most provinces this is quite easy to do. Kindergarten is still widely considered optional and many families in the disability community opt out whether it is due to the stage of development of their child, or related to infection risks or other family circumstances or beliefs. There are many homeschool communities across Canada and can be a very supportive environment for those with developmental delays and learning styles that are experiential in nature and/or sensory issues. Homeschool comes in many formats and it is a worthwhile option to explore. Some families have indicated their ability to create a closer knit community through these groups, and enables them to take turns during the week planning a homeschool day with local families, giving them a day off in turn while their child goes with another homeschool family. Some call these homeschool pods.

Chapter 9 - KISS- Keep It Super Simple: Techniques for Making Learning Meaningful

By Emily Taylor-Snell, M.Ed., Project Coordinator, US CdLS Foundation

When children have difficulty accessing and processing basic communication and information, it is our job to KISS – Keep It Super Simple! Emily Taylor-Snell's presentation at the 2016 United Stated CdLS National Family Conference had participants look at learning from the child's perspective so they can see how to set up activities. This interactive, demonstrated and practiced techniques help children maximize their vision, develop tangible communication systems, and practice hand-under-hand techniques in learning motor tasks.

Basis of Content

The tenets of the presentation were drawn from evidence based practice in working with children with dual sensory loss and other complex needs taken from the work of Jan van Dijk, Barbara Miles, Kat Stremel, Charity Rowland and Phil Schweigert. A few communication techniques presented at the session were:

1. Use objects or pictures for communication for choice & requests

2. Don't anticipate every need, create need to communicate

3. Develop name signs for people and pets

4. Make sure activities have a clear beginning, middle and end Declutter pictures and areas and use colour contrast

5. Pause for "more" and turn-taking and transitions between activities

6. Hand-under-hand technique vs. hand-over-hand technique

7. Routines based learning: Shows HOW activities are done

8. Calendar Schedule: Helps anticipate what activity is NEXT

9. Include child in daily chores and community activities

10. Use fewer commands and have more fun conversations

11. Do things together—have two similar items

"Be consistent and patient."

Ways to engage Early Emergent Literacy, Emily Taylor-Snell suggested:

- Label Objects Recipes
- Choice Making
- Logos and Packaging Labels
- Experience Books Games - that include matching and sorting
- PowerPoint Books

One success story using KISS:

We'd like to thank Kartik's parents, Padmini & Praveen, for sharing their story with us. At the 26th Biennial National Family Conference in Orlando, Florida, one of the components that we took away was the workshop KISS- Keep It Super Simple: Techniques for Making Learning Meaningful and our interaction at our consultation with Emily Taylor-Snell. We learned about the importance of overall communication and encouragement of all modes of communication, along with making adaptations to lighting, brightness, positioning and contrast. We have started to encourage Kartik to sit parallel to an object positioned with lighting from behind; we have noticed his eye tracking an object is much better than before. We also noticed that once the lighting and vision is controlled, he seems to balance his body better in that space. Secondly, we are approaching him with objects then handing them over to him; we use sign language while doing this so he can start making choices. He has sporadic responses, but on the positive side, he is beginning to understand that communication is two-way. He is communicating in other ways, such as asking to be picked up. Lastly, by playing more "Singing Time with Alex and Leah" videos and rhymes on YouTube that are played by kids (which he loves), he is starting to identify with the child in the videos and responds to the voice of his teachers and therapists. We feel we have gained immensely with our interaction with Emily Taylor-Snell. The best part about the workshop and consultation was learning easy tips that can be done at home and outside. This information enriches our daily experiences and has shown positive results.
Thank you Padmini & Praveen.

Chapter 10 - A Closer Look: In the Classroom

Learning is a foundation of life, and regardless of a person's cognitive or physical limitations, she/he has the ability to learn. For children with CdLS, like five-year-old Emily, a structured learning environment is essential to development. And throughout the learning process, teachers, like Emily's teacher, Janet, find themselves learning valuable lessons from their students with special needs. Emily has been Janet's student at Newtown Preschool, since she was three. Although she teaches a variety of students with special needs, Janet had no prior experience with, or even knowledge of, CdLS. Throughout their years together, Janet learned about the cognitive effects of CdLS, along with how best to help Emily succeed educationally amidst her many inherent challenges. During the 2008-09 school year, Emily attended school two full days and two half days each week. While there, she participated in physical and occupational therapy twice a week, along with daily speech therapy. At school, Emily received one-on-one attention, which helped her focus on the task at

hand and learn at her own pace. During this time, Janet used Applied Behaviour Analysis (ABA) techniques, which provide structured activities designed to reach a variety of learning goals. With a little help from her teachers, Emily has learned how to spell and write her name, understands and communicates more than 70 signs, counts, and colours. She also took on independent tasks, such as feeding herself and washing her hands. Towards the end of the school year, her teachers and speech therapist introduced a new "Go Talk" augmentative communication device to supplement and enhance her communication skills (see page four for more information about communication devices). Emily's classroom has always been integrated, with about half of the students having special needs. This integration allows Emily to grow socially and learn to communicate with her peers while promoting acceptance among all classmates. Playtime focused around different play stations, in which Emily interacted with other classmates for a specific amount of time. And at "Circle time" Janet led Emily and her classmates in reading, singing and dancing, all of which were accompanied by basic sign language. Communication between Emily's teachers and her parents was key. Throughout the year, teachers sent home daily reports of Emily's activities, behaviour and accomplishments. "This communication with Emily's teachers was very important to us because we wanted to know what she was learning so we could build upon it at home," said Lori, Emily's mom Emily has made great strides, literally. "When she first went to school, she couldn't even walk," says Lori. "Now, she's running." This fall, she'll be running right to kindergarten.

Chapter 11 - Assisting the Social Development of Children with CdLS

Article from Reaching Out (March/April 1997)

For young children with CdLS, family and school settings are primary areas where social and communication skills are learned and developed. During a workshop at the Foundation's 1996 conference in Tennessee, Dr. Samuel Odom, of the John F. Kennedy Center in Nashville, discussed ways families and educators may promote a child's social development by providing opportunities for inclusion in activities at home and at school.

For children in general, social competence -- meaning the ability to socially interact in an effective, responsive and appropriate way -- starts even before a child learns to speak. With children who speak very little, the time parents spend interacting with their child helps prepare them for future interactions with adults or other children.

Interactive games that are done just for fun, like patty-cake or peek-a-boo, help develop social skills that require an understanding of taking turns during an activity. Children pick up on the notion of what it means to take a turn, when parents or friends play games that leave an opening or a time slot for their child to respond.

Dr. Odom pointed out that it is also important for parents to talk to their very young children, even if they don't understand exactly what is being said. The experience of being around a talking, interactive adult is positive for children with or without special needs. Again, it is important that parents remember to take turns, either verbally or by their behaviour, so the child may respond.

Parents may also imitate what their child is saying, even it is simply a sound or babbling. This kind of imitation early on in the first year and a half of a child's life is an especially productive way to gain a child's attention.

Children Helping Children

In creating programs in the area of social development, Dr. Odom found that an essential element is giving children with disabilities the opportunity to interact with socially competent peers -- peers who are good players and talkers.

"The developmental benefits are clear, he said, "for placing children with disabilities into settings with children without disabilities. Children who have good communication and social skills help children with special needs learn and practice ways of talking and communicating that they might not be able to do if other children in the classroom didn't have that kind of communication ability." In many cases, this is accomplished in a setting where teachers know how to set up an environment that will support children with special needs and foster the development of social relationships. Social

relationships can mean a broad number of things, but include friendships and acquaintanceships. For children with a range of special needs (not just children with CdLS), some are socially competent and can establish friendships or other positive social relationships with their peers. Other children, who may be more limited in their play, communication and social skills, can get support for developing those skills from other children.

Teachers can use different strategies to promote acquaintanceships and social relationships during school activities, including finger plays, songs and games that lead children without disabilities into positive interactions with other children who may not have a lot of social skills. "Simon Says," a familiar childhood game, is excellent for encouraging this type of positive interaction among children. For example, if "Teresa" is a child with special needs in our classroom, and we want to make sure that other children in the class get to know her and interact with her, "Simon" can say, "Let's all smile at Teresa," or "Give a hug to the person sitting next to you." This type of activity in the classroom is both social and positive in nature, and can be turned around to involve children who might be left out.

Peer buddy systems are another approach that teachers use in the classroom, where children "buddy up" with a child with special needs for part of the day. Activities such as this should come out of the education plan that special education and early intervention teachers will develop for your child. As parents, you can help your child develop positive social relationships, by making sure that social goals are a part of his or her special education or pre-school program. Let your child's teacher know that your child needs time during the day to be around other children who have typical social and communication skills.

Also, remember it is important to increase social opportunities for children outside of traditional preschool settings. Parents tell us that opportunities present themselves in playgroups, churches, summer camps, and even by playing with their brothers and sisters -- all extremely useful experiences for young children who are learning how to become interested in other people and their environment.

Dr. Odom found that opportunities for a child to gain social and communication skills in an inclusive setting are too important to be overlooked. If you would like to talk to another parent who has had a positive experience with this type of program, give us a call. Also, a limited number of videotapes of Dr. Odom's presentation at the annual conference in Nashville are available for viewing. For more information, please contact the Foundation.

Chapter 12 - Adapter Physical Education

Geir Rosvik, Adapted Physical Education Specialist, Seattle,WA, Public Schools and dad to Iselen

Students with special needs are required to receive at least the same amount of Physical Education (PE) as students who are typically developing. Federal law defines PE as the development of physical and motor fitness, fundamental motor skills and patterns, and skills in aquatics, dance and individual and group sports (including intramural and lifetime sports).

Some students with disabilities are able to participate in regular PE activities. Adapted Physical Education (APE) is PE that is customized and modified to address the needs of the individual. Schools need to offer equal access to extracurricular activities for students with disabilities. Extracurricular activities include club, varsity, and intramural sports programs. The following are core principles that should be applied when providing APE to students with disabilities.

Safety
When developing a plan, teachers and other staff need to determine students' abilities and consideration should be given to things such as range of motion, weight bearing, and sensory issues. An example for a student with limb differences might be lowering an activity to the floor, using assistive devices for the affected limbs or designing an activity that uses the unaffected limbs. Teachers should adapt activities to meet the needs of the student, rather than expect the student to adapt to the activity.

Placement

Adapted PE services should be provided in the least restrictive environment possible. Laws requiring integration of students with disabilities could not be clearer; students with disabilities should have meaningful participation, equal opportunities and inclusion with students without disabilities to the maximum extent possible. Success has been found in classes where teachers have developed peer partners in the classes. Peer partners are students without disabilities who work with the student with a disability to facilitate that student's participation and inclusion. IEP APE can be included in a student's Individual Education Plan (IEP). Sometimes parents/guardians need to advocate for their sons or daughters to have APE on their IEPs.

Classroom structure

Universal design of the classroom meets the needs of a broad spectrum of learners. Examples of universal design are a consistent structure, visual schedules, attention to transition, grab bars on the walls, three dimensional cues, class wide peer partners, the use of sign language and using auditory, visual, gestural and physical prompts. I try to provide a variety of activities using multiple strategies when I work with students.

Adaptations and modifications

The environment may need to be changed to meet the needs of the individual student or students. It is important to determine what activities the student likes or desires to do. Activities should be broken down into tasks and skills. The teacher needs to determine what the student is able to do, if the activity needs to be changed, what equipment is required and what supports are necessary. Some examples of adaptations are short, simplified rules, shorter or longer playing time, rule changes, increased rest time and slowing down the game, lowering the target, increasing the goal size, making the field smaller and removing obstacles. Games may be played sitting or lying down. The equipment may be smaller or larger, a different colour, varying textures, lighter or softer. Balls may be suspended from stationary objects or partially deflated.

Activities

A variety of organizations provide recreational opportunities for people with special needs. Special Olympics is a great community where individuals can participate in a variety of sports and they often are well connected in the community.

Lifetime activities

Our family enjoys recreational activities with Iselen, our daughter who has CdLS. These activities include, biking, swimming, hiking, dancing and walking the dog. Our family focus is on improving her lifetime fitness skills that will improve her overall health.

As an Adapted PE Specialist, I believe we are limited mostly by our lack of imagination and creativity regarding participation by students with disabilities in PE and extracurricular activities. We as parents and caregivers can make a difference in our sons' and daughters' lives by offering them opportunities to participate in recreational activities both in school and in the community.

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Chapter 13 - Your Child's Individualized Education Plan

By Jenni Glad Timmons, BScN. RN. AltMBA. DNP.

When a child has been identified as an exceptional student an Individualized Education Plan (IEP) will be developed annually and reviewed throughout the year. It is important to understand that the IEP is a legal document that the School Board is required to develop in consultation with the family and implement the IEP and evaluate the IEP. It is important to know the legislation around IEPs and your role as a parent in advocating for your child in the development of the IEP. Although this may look slightly different across provinces it is defined in the Education Act. Here is a sample of the Ontario policy surrounding the IEP.

Ontario: https://www.ontario.ca/document/special-education-ontario-policy-and-resource-guide-kindergarten-grade-12/components-iep

IEP meetings are important meetings that we recommend that you prepare for. Take some time in advance to consider your child, what would make his/her learning experience successful from transportation to and from school, transitions, managing sensory inputs, behaviour plans, learning styles, toileting, medical or feeding needs etc.
IEP meetings typically occur in the first month or two in the beginning of the school year, each province and school board has their dates in which the meeting needs to happen and a timeline for you to provide feedback on the document. This is your opportunity as a parent to have a legal document that describes what the learning goals for your child should be. The IEP contains domains of learning whether academic components or lifeskill components or a combination of them all. Before the school year begins, take some time to review the previous year's IEP, or if this is your child's first year of school, you may want to engage your child's therapists and their goals for your child. It is always beneficial for the child to have integrated goals between home, school and therapies.

It is important to prepare for the meeting. Bring together all your child's other goals from therapy and things they are interested in achieving a home and in their community. It is always much easier to integrate the goals across the different environments of the child's life where possible. We always recommend to bring another person along to take notes, and leave one person to ensure you will cover everything you have prepared and want to be heard. After this initial meeting the school team will come together and create the IEP which you will be able to provide input into. This is critical. Many families are not often aware of the process for the IEP and it is not always clear. You will want to provide your input to the IEP in writing. There is often little space for your input and therefore we suggest that you take a separate document and write on paper or type your feedback. This is your time to advocate and ensure that the plan for your child's learning is appropriate. You know your child best. Know your rights and be confident in your feedback. Avoid using language that gives a softer option for them. There are many methods to word IEPs in a way that they are achievable and one such method is using SMART goal format which stands for Specific, Measurable, Attainable, Relevant and Time specific.

Chapter 14 - Addressing Behaviour Concerns

By Shelly Champion, M.Ed.

Many individuals with CdLS, exhibit some challenging behaviours. Before describing the behaviours and some techniques to alleviate behaviours, it is important to realize that behaviours serve a function for the individual. It could be to express discomfort or a desire. When an individual has challenging behaviours, the first step is to rule out any medical and/or physiological problems that may be causing the behaviour such as gastric reflux, ear problems, diet, sinus problems, dental decay, etc. Challenging behaviours often occur when an individual wants to get a message across so they can get what they want. When observing behaviours, it is important to observe events that happen right before and after the challenging behaviours. Through these observations, parents, caregivers and teachers can find what might trigger the behaviours and design the environment in a way to reduce these triggers and reactions, which can make the behaviour occur less in the future. Some individuals with CdLS exhibit self-injurious behaviour (SIB). "Some forms of SIB include hand biting, head banging, head hitting, hair pulling, eye/ear poking, self-scratching and skin picking…After assessing and ruling out any medical issues, including those listed previously, the next step is to seek behavioural services (psychologist, Board certified Behaviour Analyst, etc.)" (O'Connor). Some individuals may need protective equipment, such as a helmet or arm splints. The use of this equipment allows for assessment of the behaviour while preventing any physical damage. While using equipment that reduces range of motion, be sure to check for signs of irritation. Other problem behaviours in individuals with CdLS may include aggression, tantrums, disruptive behaviours (tearing objects) and non-compliance. A professional should conduct an assessment to identify the function of the challenging or target behaviour, which can vary between individuals. A functional assessment is conducted, sometimes called an FBA (Functional Behavioural Assessment). Behaviour is observed over a period of time to monitor the antecedents (what happens before) and consequences (what happens after) of the target behaviour. Some typical functions of behaviour are attention, wanting a desired item, or escape from demands. The

assessment should also document if there is a pattern, is the behaviour situational, does it occur at the same time, same place or with a particular person. Once the function is identified, intervention can begin. The goal of the intervention is to reduce the undesired or challenging behaviour and replace it with a desired and preferred behaviour. Additionally, replacement behaviours, such as communication or play skills, should be taught. Individuals with CdLS have behaviours that are similar to behaviours exhibited by individuals with autism, therefore some treatments and techniques are similar. "Extinction is a common treatment. When using extinction, you want to do the opposite of what the child is trying to gain from the behaviour. For example, if the child is using SIB to get out of doing work, you want to make sure the child completes the work presented. If the child is seeking attention, make sure you do not give it to him/her. For behaviours maintained by attention, you would start by teaching the individual a communication response to request attention, while ignoring SIB." (O'Connor) "Other strategies include providing a schedule of positive attention, reinforcing the absence of the problem behaviour or increasing reinforcers in the environment. Remember that the same items do not motivate all individuals, so it is important to identify specific reinforcers for the individual. For example, one might find chocolate reinforcing, while another might prefer [stickers]." (O'Connor). Reinforcers for individuals also change over time.

For self-stimulatory behaviours, one strategy is to provide alternate sensory input that replaces the need to self-injure. Another strategy is to use sensory extinction, which means to prevent the sensory input from the SIB by using helmets and padding to cover the targeted areas. For example, if a child is pulling their hair, splints may be uses to prevent this from happening. "The use of a response reduction procedure when other interventions are insufficient may be evaluated. This might be a brief, time-limited consequence such as time out of the room. When used, a time out procedure should demonstrate a quick reduction in the problem behaviour and can be faded over time." (O'Connor) If the function of the behaviour is to escape a situation or task, time out is not an option because it reinforces the function of the behaviour (escape). If the individual is exhibiting neuropsychiatric symptoms, such as mood problems like depression or excessive anxiety, then a medical consultation should be included. Medications could be considered if behaviour interventions do not work. "The best approach to problem behaviours in individuals with CdLS is a comprehensive assessment by a team of professionals to determine the most appropriate treatment, which may include medical intervention, medication management, and behavioural approaches, as well as other strategies to attain the best outcome. While this is an ongoing process, it is important to remember it is possible to decrease undesired behaviour in individuals with CdLS." (O'Connor) The list of classroom suggestions included in the appendix of this handbook will help in preventing some behaviours. Some other key points are:

- Behaviours change as a child develops as well as the function of the behaviour for verbal and non-verbal individuals.
- Behaviour communicates something.
- When using a technique, target one behaviour at a time.
- Keep a log of the behaviours and include antecedents, consequences (what happens before and after the behaviour), where and time of day the behaviour takes place.
- Time and patience are crucial. There is no quick fix for behaviour issues. Be sure that whatever your response is to an unwanted behaviour, it does not create other behaviour issues.

Behaviour Plans in Your Child's Individualized Education Plan

By Roger Woerner, B.S., SpEd., US CdLS Foundation Educational Advisory Group

I have been an EBD teacher for a number of years. What's that you ask? Well, if you've been to meetings with professionals who work with children who have special needs, you know we like to throw around letters of the alphabet. EBD means Emotional and Behavioural Disorder.

Let's get this started with some sayings for you to remember. First, the barking dog gets the bone. That means if the "pros" (as I will call school personnel), say anything you don't understand or you disagree with, it's time to say, "hold your horses."

Two things have been proven:

1) Every child can learn; we are simply talking about the time it will take, and
2) if the pros are seeing a behaviour, then there's a reason for it.

The reason why a behaviour is happening is sometimes the hardest thing to figure out. Behaviour is communication. Often the parent's input gives the pros insight to why the behaviour is occurring. Are the pros saying "this child IS a problem" or "this child HAS a problem." There's a big difference between the two statements.

A Behaviour Improvement Plan (BIP) is a serious process to add to a student's Individual Education Plan (IEP). It says that the student has a behaviour problem that is interfering with his/her educational progress. You are stating that the child's behaviour plan is part of their educational needs for success in school. This will be reviewed and updated each year and follow him or her from teacher to teacher and school to school. A BIP must be followed across all educational settings with every "pro" who works with your child. This is not to say the child is bad, but that they have special needs and there is a protocol to follow, if needed.

Before a BIP is implemented, a Functional Behavioural Analysis (FBA) must be performed by a qualified person (school psychologist). And before a FBA is performed, hopefully you have worked extensively with the teacher and tried some interventions. Interventions are ways of redirecting an undesired behaviour. To change a behaviour you must have the patience to teach and reteach the desired behaviour, at home and school. This is hard to implement at home with one child, so you can imagine a teacher having the time and patience to work with a student with a BIP. Be supportive of the teacher. The teacher and parent must form a partnership to come up with meaningful incentives and consequences for the desired behaviour. By saying meaningful, I mean meaningful for the child not the teacher or parent. Interventions should be tried (with a little modification) for six weeks before it can be judged as successful or not.
The following is a list of information to document during this process:

1. Are there antecedents to the behaviour? (what happens before the behaviour begins?) If so, is it predictable or is there a consistent pattern?
2. What's the environment of the behaviour? (where does it occur and not occur, e.g., with certain people, places, level of noise?)
3. What does the child hope to get from exhibiting this behaviour? (attention, timeout, etc.)
4. What behaviour can be replaced to gain the desired results?

If the interventions fall short, then a new FBA must be preformed. This also takes weeks and a lot of paperwork. You will be contacted by several school officials asking to meet with you and asking for permission for several things, such as contacting your doctor, observing your child, and testing your child.

Upon completion of the FBA, your child's IEP team will decide what action will be best for your child. For a BIP to become legally part of a student's IEP it must: be stated in a positive manner and describe the behaviour you want to see; be measurable (a certain percent of the time or how many minutes); and define the environment where the said behaviour should be seen (in the classroom, the gym, etc.).

The BIP along with the FBA can be very useful tools, when used correctly with the parent's partnership with the teacher. Gathering useful information during the process can mean the difference between correcting an unwanted behaviour or not.

In addition to being an EBD teacher in Texas, Roger is the father of Michael, 24, who has CdLS.

Appendix 2 - some sample behaviour IEP goals

Chapter 15 - Cerebral/Cortical Vision Impairment (CVI): What you should know

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

This article expands on the March/April 2005 article (on "CdLS and The Eye" written by Drs. Berger, Schloff and Schoedel, describing the implications of many structures of the eyes and various conditions common to persons who have CdLS) in regard to the educational, communication, and social aspects related to visual functioning. "CVI" or "cortical/cerebral visual impairment" is an often overlooked condition that affects many children with CdLS, impinging on not only their vision, but also their ability to learn and interact with their environment.

Vision is complex. It requires:

(1) the ability of the eyes to receive visual information,
(2) the brain's ability to process the visual information in combination with and at the same time as other sensory information and
(3) motivation to use the visual system.

All people with CdLS should have examinations by an ophthalmologist or optometrist to determine, as much as possible, the health of the eyes, how clearly they are able to see visual information and/or if they have conditions that may be relieved by surgery, glasses and/or other means. It is the eye that takes in the visual information.

However, it is the brain that processes the information and allows us to understand the visual messages the eyes receive. Understanding all the information the eyes receive may be difficult for some persons because it takes many areas of the brain, working as a team, to process such information. Thus, a major challenge for many people is in understanding the visual information. Finally, effective use of the visual system requires motivation. It is a lot of work to (1) determine what to look at from the vast array of visual images that bombard us almost every waking hour and (2) coordinate the movements of the ocular muscles in the right direction, track and scan. The most critical aspect, as related to motivation, is the desire to learn from and socially interact with the environment.

Understanding Visual Information

There are some persons with CdLS who have visual behaviours similar to those individuals who have been diagnosed with cortical/cerebral visual impairment – otherwise referred to as CVI. CVI is a disability resulting from either an insult to the brain or how the brain was configured during prenatal development. CVI affects how the brain processes the visual information received by the eyes. Many persons with CVI display wide variations in the functional use of their vision, not just day-to-day but also minute-to-minute.

People with CVI also tend to display some/many of the following behaviours (very few persons have all these behaviours):

- Great variability in how they use their eyes from being visually attentive at one moment and visually inattentive at another moment. May appear to stare into space.
- A tendency to use peripheral vision more than central vision. The midline is rarely the preferred gazing orientation.
- Limited visual attention and a seeming lack of visual curiosity about their environment/surroundings.
- Great difficulty in looking at crowded or complex visual displays for informational purposes.
- A tendency to want to get close to the object(s) they are viewing either to magnify the image or to reduce the complexity of what they are looking at.

- A tendency to be light sensitive and/or a tendency to gaze at lights. Some individuals gaze at light even though they are light sensitive.

- A tendency to look away when reaching.

- A tendency to avoid looking at the human face OR a tendency to stare at the human face OR a tendency to stare at just one part of the face.

- Difficulty in managing multi-sensory demands and planning/implementing motor responses; relying mostly on other senses for help/information.

- Possible depth perception difficulties which may affect accurate reaching for objects and/or mobility.

- Many people with CVI have difficulty in making the quantum leap of learning from three-dimensional objects to two-dimensional line drawings or photographs, except when trained picture-by-picture. Even then, it is difficult for many to generalize the understanding of these pictures to different environments and situations.

- For many who are print readers, there may be inconsistent difficulties interpreting print, a need for larger and bolder size print even though visual acuity is near-normal, and a short attention span when using print materials. The latter frequently is due to visual fatigue as a result of the effort to see and interpret the crowded visual symbols. The major difference between readers with CVI and readers with learning disabilities is that the former is inconsistent. At one moment the person may be able to read well and in the next moment, not be able to read at all. With learning disabilities, there is more consistency in the type of problems related to reading.

- Difficulty in using vision when moving OR difficulty when the object is moving. Some people may have difficulty when there is no movement. This may make moving around in the environment difficult.

- Difficulty in discriminating between and identifying people based solely on vision, relying on the other senses for information. This is called prosopagnosia or, in its more extreme form, facial agnosia.

Numerous other possible behaviours may be associated with CVI including difficulty in understanding the full range of language used by others as well as the language they, themselves, use. Such communication difficulties may range from people who understand only the emotional and melodic aspect of language to other people who may talk a lot but have significant difficulty in understanding the social aspect of the verbal exchange.

<u>The Implications of Cortical/Cerebral Visual Impairment (CVI) for Students Who Have CdLS:</u>

A primary implication of CVI is the confusion that is created for families and professionals unfamiliar with this condition when visual interest is not obvious or is demonstrated only occasionally. Such confusion is even greater when the medical eye examination is relatively normal. Such variability in visual responsiveness may be highly dependent on the person's level of fatigue, stress, medication, motivation for the task, competing sensory demands, position, and motor requirements of the task. Visual behaviours also may be highly influenced by physical challenges that do not allow the person easy visual access to the environment and by the nature of a seizure condition, should that exist.

Another primary implication of CVI, especially in relating with students who have CdLS and do not talk, is the monumental task in determining what type(s) of communication systems would be the most appropriate. It with must be understood that the use of line drawings (e.g., Mayer Johnson), photographs and/or print assumes the ability to interpret abstract visual symbols. As part of this consideration, it is critically important to remember that when a person looks at something, the visual gaze does not automatically translate into understanding (although it does show interest). The difficulty in understanding may be due to a lack of appropriate visual experiences, a cognitive status that does not support understanding two-dimensional abstract representation or a form of CVI. Thus, when planning what type of communication system might be introduced to a student who does not talk, the following must be considered:

- Does the student demonstrate many of the behaviours described previously that might suggest there is a possibility of some degree of cortical/cerebral visual impairment?
- Does the student consistently demonstrate knowledge of object function and anticipation of the subsequent activity based solely on looking at an object that is an integral component of the activity? If the student cannot visually interpret the three- dimensional world (e.g., objects), how can the student be expected to interpret the two-dimensional world (e.g., pictures, line drawings)?
- Does the student prefer to use objects to communicate while rejecting the use of pictures, line drawings and/or communication devices (for more than cause & effect purposes)?

Finally, the diagnosis of CVI is not restricted to persons who have severe and obvious physical and/or cognitive challenges. Nor is CVI restricted to persons who do not talk or those who have acuity measurements in the visual impairment range. Recent research has demonstrated that CVI also may be a "hidden disability" for many walking, talking academic students who also have near-normal visual acuity. Diagnosing CVI is difficult when there is no focal brain insult. The best diagnostic methods to determine CVI include the medical eye care examination and systematic observations of functional visual behaviours by families and involved professionals. It is especially helpful to have a certified teacher of the visually impaired, who has training and experience cortical/cerebral visual impairment (CVI), as part of the diagnostic team. Many students, with and without CdLS, have been given visual communication systems without appropriate and thorough observations of their understanding of visual information. Such decisions may have a life-long impact on the educational, communication, and social aspect of these students' lives.

Chapter 16 - Educational Techniques for Children with CdLS

By Shelly Champion, M.Ed., Karen Aschenbrenner, Linda Blumkin and Lianne Lessa, Jenni Glad Timmons RN. BScN. DNP.

The following is a list of techniques that have been successful for individuals with CdLS:

- A calendar system that the student uses and understands about what will happen during the day. Pictures or objects will show what is happening next and removing picture/object when task or activity is finished.

- Regular routines so that the student can anticipate what is happening next; knowing that some favourite activities are looked forward to, others are dreaded, and realizing those activities may be shorter, followed by a favourite one.

- Use visual and or oral cues for first - then activities. Prepare the student for transitions orally and pictorially.

- Using task analysis or breaking down an activity into sequential steps is beneficial, as well as using visual prompts.

- Provide transitions from one activity to another; knowing there will be a beginning, middle, and end to the activity. Carrying an item from one activity to another helps with a transition, such as carrying a crayon to art class or ball to gym. Using a song to sing between transitions or other visual cues such as jumping over a families rope of the ground for example, can be another option to support transitions.

- Making choices of food, toys, books, music, clothes, almost everything to give the individual power over what happens in their life. The choice can be controlled through having a choice from two desired items, such as red shoes or blue shoes. Too much choice can cause anxiety for some.

- Include explicit instruction in social skills in and outside school settings. Social stories and role-playing are two very good techniques.

- The child's environment should be organized, have structure, routines and schedules built into the day, with choice making a regular part of the day. The less clutter in a classroom and on the walls the better.

- A child with CdLS can often benefit from being in the front of a class if in a mainstream classroom to support minimizing visual stimulus and support focus and learning

- The most desirable characteristics of an educational setting is for it to be nurturing, caring, secure, safe, responsive, friendly and stimulating, with clear, consistent behavioural expectations.

- Administer a Functional Behavioural Analysis (FBA) to determine the function of a behaviour and noting the antecedent, behaviour, sequence. Is the function of the behaviour attention, escape from task, or to get a tangible item? From the FBA develop a Behaviour Intervention Plan (BIP).

- This should be included in the student's IEP. All participants at home and school should be involved in developing and implementing this plan.

- The individual should be evaluated by an OT for any sensory issues. It has been found that many children with CdLS are irritated by noise and the commotion of having many people around. In school, this could be the lunchroom. Some sensory activities may be calming and reduce stress such as vestibular activities, brushing and pressing, proprioception, bouncing, swinging and chewing. Strong smells, abrupt loud sounds and too much visual stimulus can exhaust an individual with CdLS who has sensory sensitivities or sensory processing disorder. Some individuals continue to have naps throughout their adolescents or need quiet time in a quiet low lit room without any stimulus. One 9-year old girl finds a small bubble chair with a fold down screen a secure place to charge and withdraw from overstimulation.

- Spending time with non-disabled peers for social time, while doing age appropriate activities.

SOCIALIZATION, MAKING FRIENDS & RECREATION

Tips for Social Participation

- Participate in community resources such as PTA school- sponsored activities, and recreational facilities that strengthen your child's sense of belonging and build friendships.

- Communicate regularly with educators, administrators, para-educators and other support staff to share feedback. Keep a journal or log to organize your ideas while monitoring your child's progress.

- Identify and build on the strengths and abilities of your child as well as the family as a whole by incorporating individual and shared activities that are both achievable and realistic.

- Promote extracurricular activities that interest your child and use his or her strengths. Provide leadership opportunities for your child that make a notable contribution such as completing chores for neighbours or reading to a younger student.

- Ask for help when needed. The school team is ready to listen and will answer your questions.

- Model positive behaviour by listening to your child's concerns, demonstrating problem solving and making healthy lifestyle choices for you and your child.

- Monitor your child's habits and routines in sleep, diet and activity. Note any significant changes, and share this information as appropriate with school medical professionals.

Many children's rehabilitation centres have a recreation therapy program where an individual can get support with engaging in recreation, socializing with others and engaging in the community. A Certified Recreation Therapist can be an excellent resource and support to create and achieve your child's social goals.

Many families have found a community through connecting with other families nearby with children with CdLS, join Special Olympics or other community groups that create events and social activities for individuals like those with CdLS.

Many families have found other parents through the school to arrange play dates with and can become lifelong friends and a support network.

During adolescents individuals with CdLS may crave friendships and social outings but they may not be able to organize them alone. Having community connections makes it easier to coordinate outings and find resources and activities to do for your teen.

Chapter 17 - Communication and CdLS

By Shelly Champion, M.Ed.

Children with CdLS are at risk for delayed or absent speech, difficulty in understanding the subtle nuances and pragmatics of language and/or auditory sensitivity to a barrage of speech and environmental sounds. Receptive language skills are much higher than expressive language skills in individuals with CdLS. Individuals with CdLS have a greater ability to understand than speak. For some individuals, speech is very difficult due to oral-motor apraxia. These children do not choose to talk and find the communication and production of the motor actions extremely difficult. Individuals who are unable to speak are able to learn nonverbal expressive skills. Speech may be the ultimate goal for those children who do not talk or find talking difficult. They need a way to express themselves now so that they may become more active participants in the educational process. There are varieties of educational techniques that can be employed to help these children communicate while they simultaneously work on the higher goals of speech production. Even if speech is not a realistic goal for some children with CdLS, there are educational techniques that can be employed for very effective communication. Marjorie Goodban, Ph.D., CCC-SLP, has delineated four groups of communication abilities of individuals with CdLS.

Talkers, late talkers, limited talkers, and non-talkers.

The talkers are the smallest group in which speech and language skills are within low-normal limits but they will eventually use normal speech and language skills. The late talkers are mild to moderately late in acquiring speech, but will eventually use three to five-word utterances. The limited talkers are severely delayed in acquiring speech, but will eventually communicate in one to two-word utterances. The non-talker group will not develop any speech or language. For individuals in the talkers' group, placement is often in a regular classroom with help receiving speech therapy focusing on speech sounds, grammar, loudness, and social language. For late talkers, typical therapy procedures include speech-language stimulation, gestures and sign language to facilitate learning, self-talk, parallel talk, and drill and repetition for longer utterances. For limited talkers and non-talkers, interventions include Augmentative and Alternative Communication (AAC) systems, oral-facial stimulation and feeding therapy, and treatment programs for autistic and deaf/blind population. AAC is any device or method that improves the ability of an individual to communicate effectively. Some devices include communication boards, voice output communication aids (VOCAs), Picture Exchange Communication System (PECS), object communication, gestures and sign language. AAC systems can facilitate the development of language when used in conjunction with oral language. When choosing a method or combination of methods for communication, an assessment of understanding is critical in determining what mode(s) of communication will have the best chance of being effective. Some children may have visual- perceptual strengths, but may not be able to understand all forms of visual stimuli. Visual regard for two-dimensional representation (pictures, line drawing, icons, photographs, print) does not automatically mean there is an understanding of this form of symbolic representation. When using any method, start slow. Don't introduce too many options at once. The child might get overwhelmed and give up on any communication attempts. It is important that what the child is communicating for must be meaningful for them (e.g., motivational). A child won't ask for a toy that doesn't interest him/her. learning, self-talk, parallel talk, and drill and repetition for longer utterances. For limited talkers and non-talkers, interventions include Augmentative and Alternative Communication (AAC) systems, oral-facial stimulation and feeding therapy, and treatment programs for autistic and deaf/blind population. AAC is any device or

method that improves the ability of an individual to communicate effectively. Some devices include communication boards, voice output communication aids (VOCAs), Picture Exchange Communication System (PECS), object communication, gestures and sign language. AAC systems can facilitate the development of language when used in conjunction with oral language.

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Many children who use sign language use modified signs. It is important to recognize that sign language can facilitate the development of oral language. Similar to sign language, a child's gestures may only be recognized by those close to him/her. In Picture Exchange Communication System (PECS), the child is taught to give a single picture (line drawing or actual picture) that corresponds to that item that he/she desires. Some prerequisites for PECS include: Does the child reach or move toward something that would be reinforcing for them? Is the child able to match object to object? Then picture to object? In the first stage of PECS, a child is taught to initiate a request: pick up and exchange a picture that corresponds to the item he/she wants. In phase two, pictures are put in the binder. In phase three, the child discriminates between pictures of desired items. Phase four builds sentence structure: "I want ball." Sentences are expanded with attributes; "I want red ball." In phase 5, the child is taught to answer simple questions; "What do you want?" "I want…" and in phase six the child is taught to make comments: "I see a spoon." Dr. Mary Morse has been successful in using schedule systems with children with CdLS. She found that children with significant language problems also have difficulties anticipating events. Using a calendar or picture schedule can assist the child in organizing his/her world, anticipating responses, and developing some structure. A calendar schedule can also aid in developing receptive and expressive communication. The calendar schedule must be understandable to the child, be it objects, pictures or words. A schedule system is highly individualized to the child. It can be series of boxes, a board with Velcro to hold objects or pictures, or even a three-ring binder. The schedule must use left to right sequence; some use vertical top to bottom presentation. At the beginning of the day or activity, the child and parent, or teacher, go over the sequence of activities for the designated period. As an activity is completed, it is put in the "all done" box. When a child is comfortable with a calendar schedule, the next logical step is to develop a week calendar and, later, a schedule-calendar for a month. To quote Dr. Morse: "The benefits of having a schedule system rests on:

(a) using it consistently,
(b) keeping it accessible to the child,
(c) acknowledging the child's attempts to communicate via the system, and
(d) showing the child any changes in the day via words/signs/gestures and changing the placement of objects or objects symbols within the schedule."

Communication boards can vary from a series of objects or pictures to communication devices. These can be homemade or sophisticated electronic devices such as a Dynovox or iPad/iPod Touch. The use of such devices would be appropriate for a segment of the people with CdLS who can use vision to see images and have dexterity to touch the images. The current electronic devices are touch sensitive and reasonably sturdy with clear images. Many can be custom programmed for the child. The device should be easy for the child to use so that he/she can eventually use the device independently. The current generation of tablets (such as iPad/iPod Touch) goes beyond communication devices. The child can use it to makes choices, read or listen to a story, make a journal using photographs, create a schedule for school, make a list of groceries with pictures, etc. They are also light and portable so the child can bring it with him/her to any place they need it.

In general, children with CdLS are at a very high risk for missing out on numerous incidental learning experiences. These types of experiences centre around the concrete world and bring together the visual, hearing, touch, and "doing" foundation necessary to manage the abstract world of symbols and transmit and receive information through communication. Any communication system should positively contribute to the child and family's quality of life.

Chapter 18 - Therapies

Individuals with CdLS often benefit from a variety of therapies. It is important to do a careful evaluation of the individual's abilities and needs in order to tailor a treatment plan to address specific needs. There are many therapies available. Some will, and should, be included in the IEP or ISP. Some therapies include:

- Speech therapy
- Physical therapy
- Occupational therapy, including sensory integration
- Adaptive physical education
- Hippo-therapy (horses)
- Music therapy
- Pet therapy
- Aquatic therapy

The articles that follow touch on some of the most popular therapies.

Chapter 19 - Speech Therapy

By Marjorie Goodban, Ph.D., CCC-SLP

Articulation

Children with CdLS often have difficulties making sounds, a condition which speech-language pathologists identify as an articulation disorder. In the context of speech, the term "articulation" refers to structures in the mouth touching or articulating with each other. We articulate our speech sounds by making precise movements with our articulators—our tongue, teeth, lips, jaw, and soft palate—and coordinate these movements with correct airflow. For example, in order to articulate the "t" sound, we quickly touch and release our tongue tip to the area behind our upper front teeth as we release a puff of air. An articulation disorder involves mispronouncing speech sounds by omitting, distorting, substituting, or adding sounds, which can make speech difficult to understand.
Children with CdLS may say "cak" for "cat," an example of substituting an incorrect sound for the correct one. This particular sound substitution pattern is common in children with CdLS, possibly because most have a retruded lower jaw, meaning that their lower jaw is smaller and placed father back in their mouth in relation to their upper jaw. This structural difference in the jaw also places the tongue farther back in the mouth, contributing to the child's tendency to substitute the "k" for another consonant. The speech of children with CdLS is often difficult to understand. Mis-articulations are part of the problem, but there are other contributing factors, one of which is the muffling impact of the smaller than normal mouth, or oral cavity. Another factor is the frequent presence of a somewhat harsh voice with lower than normal pitch.
Speech and language are different from each other. Speech is the verbal means of communication. It includes articulation, voice (the sound of your child's voice), and fluency (whether or not your child stutters). Language is the learning of rules for communication, such as the meaning of words and how to put words together. Speech-language pathologists tend to believe that it's more important to work on language development first and speech development later. Even though your

child's speech-language pathologist may tell you that your child has an articulation disorder, she may also tell you that its treatment isn't the primary therapeutic objective. Initially, it's more important that your child have a name for the important people and events in the environment, regardless of how he or she says that name. When it's time to start the treatment for the articulation disorder, procedures are similar to the treatment process for other children with developmental delays and Childhood Apraxia of Speech.

Selective Mutism

Selective mutism is the total lack of speech in one particular situation, despite the ability to speak in other situations, with duration of this behaviour for at least one month. It's assumed that anxiety underlies this behaviour and treatment is usually a multidisciplinary approach led by a psychologist. The other members of the team usually include a speech-language pathologist, a teacher and sometimes a social worker.

Will My Child Speak? Predicting Speech and Language in Individuals with CdLS

By Janette Peracchio, M.Ed.

Since 1982, the US CdLS Foundation has had the good fortune to have Marjorie Goodban, Ph.D., CCC-SLP, as a dedicated professional and advisor to families who have children with CdLS. She has traveled all over the world, providing therapy and assessment for hundreds of individuals with the syndrome. Dr. Goodban was the first to document successful speech therapy in a child with CdLS and show the presence of speech apraxia (impaired ability to speak) in many children with the syndrome. Dr. Goodban also put together factors that can predict, in many cases, whether a child with CdLS will talk. Dr. Goodban completed two studies of children with CdLS—one in 1993 and another in 2007. She found that children who do not talk at all, or who are severely
delayed in talking, tend to have at least one of the following characteristics:

- Moderate-to-severe hearing impairment Upper limb malformations Severe motor delay (sitting up later than 25months or walking later than 30 months)

- Deficits in social relatedness (autistic- like behaviours, no eye contact,
unable to relate to people)

- Birth weight under 5pounds (probably the least important factor)

Overall, among the children she studied, 53 percent who were older than age four combined two or more words into sentences. From this research,
she divided communication abilities into four different groups:

Talkers,
Late Talkers,
Limited Talkers, and
Non-Talkers.

(Please keep in mind that there are exceptions in all of the groups and as genetic diagnosis improves and new genes are found these will include milder cases of CdLS and be a more reflective assessment of the broader CdLS community)

• Talkers are three to four percent of the group. They have normal or near normal development of speech, and they begin talking on their own

• Late Talkers are 35 to 40 percent of the group. First words can occur between 12 and 48 months, but for some as late as eight years old.

• Limited Talkers are 20 to 25 percent of the group. First words come at 7 to 10 years and as late as 12.

• Non-Talkers make up 20 to 25 percent of the group. They usually do not develop language. Instead, they use other means of communication such as gestures, sign language, and objects and pictures.

Dr. Goodban found that children with CdLS have the ability to understand language much more than the ability to produce language. Even children with highly developed vocabularies talk very little. Oftentimes, children have higher cognitive abilities than their language skills demonstrate. Communication is a basic human need for everyone. It is important for parents and school professionals to provide children a method for communicating when they are at home and school. Even a child who develops language in later years needs a way to communicate while they are working on speech skills. Whether sign language, pictures or objects are used, if a child is able to have a two-way "conversation" with others, it helps to reduce his or her stress and frustration. When poor behaviours escalate, it is often due to frustration from not being able to communicate or not understanding what is happening next, whether at school or home. Don't ever stop talking to your child. Some individuals with CdLS begin communicating in their teens and twenties. Communicate and enjoy the remarkable connections.

Chapter 20 - Physiotherapy

By Amy Metrena, M.S.P.T

What is physical therapy? How can it help my child with CdLS? When should my child start physical therapy? Where do I find a qualified physiotherapist? These are among the many questions I receive from parents. This article explores answers to these questions and offers suggestions for parents to help their children get the greatest benefit from physical therapy, as well as guide professionals who work with individuals who have CdLS.

What is Physiotherapy

Physiotherapy is a professional service provided by a licensed physiotherapist (PT) or physiotherapy assistant (PTA). Physiotherapy helps a person, child or adult, to achieve their optimal physical function and independence. It focuses on improving gross motor abilities (such as rolling, crawling, sitting, standing, walking, and moving from one position to another) as well as strengthening weak muscles, stretching tight muscles, improving endurance and balance. Physical therapists may recommend adaptive equipment, assistive devices, and/or orthotics to help achieve these goals. Additionally, physical therapists also work to prevent the loss of movement following illness, injury, or surgery.

Common Physiotherapy Issues in Children with CdLS

Children with CdLS can be born with orthopaedic problems, which may include small hands, clinodactyly (in-curved fifth finger), a proximally placed thumb, limited elbow movement, webbing of the toes, missing or shortened limbs, and/or a club foot. While most of these orthopaedic conditions are not treated directly by Physiotherapy, the therapist must be familiar with them to adapt treatment sessions as necessary. A club foot may necessitate serial splinting, which might be performed by a Physiotherapist. A very common characteristic of CdLS is developmental delay. As children with CdLS grow, they may develop other orthopaedic conditions as the result of delayed development. Developmental conditions commonly seen include tight heel cords, tight hamstrings, hallux valgus (bunions), and arthritis. Children with CdLS typically have low muscle tone (hypotonia), which also impacts development. Occasionally, children with CdLS develop hip dislocation or Legg- Calve-Perthes Disease, for which they may be referred to physical therapy. Physical therapists work with children to treat developmental conditions, whether orthopaedic or neurological, as well as to promote development of gross motor skills. When working with a child who has CdLS, a physical therapist will first perform an evaluation. The purpose of the evaluation is to determine each child's existing issues as well as potential problems that might arise in the future. Once the evaluation is complete, the therapist will develop an individualized treatment plan. The treatment plan may include developmental activities, therapeutic exercises, balance and coordination exercises, gait training with/without assistive devices, aquatic therapy, hippo- therapy, and recommendation of equipment such as orthotics, braces, and assistive devices. The treatment program should be included on the Educational Plan (EI, IEP and ISP) as well as parent education and a home program, which will be discussed in further detail later in this article. Specific information about common conditions is outlined below.

Tight Heel Cords

Tight heel cords result when the gastrocnemius muscle (located in the back of the leg running from behind the knee to the bottom of the foot) is shortened. When the gastrocnemius is not tight, it allows the ankle joint to bend beyond a 90-degree angle when the knee is straight, allowing for a normal walking pattern with a heel to toe pattern. When the heel cord (or gastrocnemius) is tight, this cannot happen. As a result, the child will often walk on his or her toes, or will place the entire foot flat with each step rather than using a mature heel- to-toe pattern. Toe walking may be the result of tight heel cords, but may also be the cause. If a child walks on his or her toes all the time (often due to sensory reasons such as a child not wanting the bottom of his foot touching the floor), then the gastrocnemius is not able to lengthen properly and, over time, the muscles will become short. Treatment of tight heel cords should include a stretching program (both in physical therapy and at home), teaching the child to use the longer muscle once more motion is gained, and may include recommendation of ankle foot orthoses (either for use during the day or at night). The child's orthopedist may recommend Botox as a treatment. This is effective if the child has the motion but is not using it, combined with intense physical therapy. In my experience, when a child is given Botox but does not have the available range of motion (or close to it), does not wear an ankle foot orthoses after the Botox treatment, or does not have intense physical therapy, then the Botox makes little difference. If these treatments do not work, then surgery to lengthen the heel cord may be recommended by the orthopedist.

Tight Hamstring

Tight hamstrings result when the muscle running along the back of the leg from the buttocks to behind the knee becomes tight. This may be due to the child's growth (especially a sudden spurt) and/ or due to spending much of the time in a seated position (especially with knees bent). As a result, knee flexion contractures may develop. Treatment for tight hamstrings includes a stretching program (both in PT and at home), reaching the child to use the hamstrings in a longer position, and may include gait training and/or a standing program.

Hallux Valgus

Hallux valgus is also known as bunions. If this condition is not painful to the child, it is typically just observed by the orthopedist. Otherwise, orthotics are recommended. In severe cases, the orthopedist may recommend surgery in order to correct the alignment of the foot and toes. Silicone moulds for between the tows can also be created to enable alignment.

Hypotonia

Hypotonia means a child has low muscle tone. Children with CdLS commonly have hypotonia. The child's limbs and trunk may feel limp, and it will be difficult for him/her to move against gravity. It will also be difficult for the child to support himself/ herself in an upright position (sitting or standing), as the muscles will have to work harder. As a result, in sitting or standing, the child may be hunched over or have an increased arch in his/ her back. As a result of the difficulty of movement, the child may develop muscle contractures later in life from lack of moving. Physical therapy treatment for hypotonia should include teaching the family good positioning for eating, sleeping, and playing (with or without special equipment such as chairs and standers), improving muscle tone, improving midline positioning, and maintaining proper alignment of the body during developmental activities.

Hip Dislocation

Dislocation of the hip may occur in a child with developmental dysplasia of the hip, otherwise known as congenital hip dysplasia. With dysplasia, the head of the femur (top of the thigh bone) or the acetabulum (the part of the pelvis where the head of the femur attaches) grows abnormally. Typically, with dysplasia, the acetabulum is shallow and does not hold the head of the femur securely. As a result, the head of the femur may sublux (come partially out of the acetabulum) or dislocate (come fully out of the acetabulum). Children with dysplasia will have asymmetrical movement of their hips, with the affected hip not being able to move out to the side (abduct) as fully as the non-affected side. Treatment for an infant includes wearing a Pavlik harness to position the hips. The physical therapist will work with the family to teach application of the harness as well as safe ways to lift and carry the baby. For older children, a spica cast may be used, or the child may require surgery as recommended by the orthopedist. For a child in a spica cast, the PT will teach the family safe ways to lift

and carry the child, and depending on the orthopedist and the child, may teach the child ways to move and be functional in the cast. For a child who has had surgery, the physical therapist will work with the child on strengthening, range of motion, and improving function.

Legg-Calve-Perthes Disease

In Legg-Calve-Perthes disease, degeneration of the femoral head results from decreased blood supply. It progresses for 2-4 years, and will eventually heal itself. It occurs in boys more often than girls, with boys being affected 4 to 5 times greater than girls. The child with Legg-Calve-Perthes Disease may initially demonstrate a limp while walking, and have pain in the groin, thigh, or inner aspect of the knee. Physical therapy treatment may include stretching, strengthening, teaching the family exercises, and if necessary, using a walker or crutches.

Early Intervention

Physical therapy should be recommended whenever a child has a movement difficulty that limits his or her ability to perform daily activities. The earlier a child starts to receive physical therapy services, the better it is for both the child and the family. Early intervention, between the ages of birth and three years, may help to reduce the likelihood of a child developing compensatory movement strategies that may cause more problems later in life, as discussed above. Physical therapy through early intervention should focus on helping the young child with CdLS to grow and develop, supporting and teaching families in this process. Developmental activities which may be addressed (depending on what the child is able to do) include rolling, sitting, crawling, and walking. It is important for parents/ caregivers to be involved in this process.

The suggestions below will help parents/caregivers facilitate these activities:

Rolling

Position an infant or young child on his/her side, placing toys just outside reach, encouraging him/her to roll onto the stomach. While a child is on his/her stomach, if this is a difficult position, place a rolled towel or small blanket under the chest to make it easier to lift the head. Use toys that attract the child's interest to encourage rolling. Make sure that his/her arms do not interfere with the roll, moving them out of the way as necessary.

Sitting

Place a child who is not yet sitting on his/her own in a sitting position on the floor. Sit behind the child, giving support at the hips or just under the shoulders, depending on what the child needs. Gradually remove your support as the child is able to tolerate without becoming upset or falling. Another activity is to place the child seated, facing you, on your thigh, with your hands under the child's arms. Bounce the child on your lap, or gradually rock from side to side. Ask the child's therapist to show you ways to teach your child to move from lying down to sitting.

Crawling

Help the child to move onto hands and knees. If this is difficult, place the child on hands and knees over your thigh while sitting on the floor. This will give the child more support and help him/ her feel more secure. Once this is easy for the child, or the child is able to maintain this position independently, encourage crawling by placing toys of interest just outside of reach.

Standing/walking

Encourage a child who does not walk to stand by positioning favourite toys just outside reach on a surface above him/ her. Help the child to pull up to standing at the surface, such as a couch or coffee table. Stay behind the child with your hands on the child's buttocks or back, as necessary. Encourage cruising (walking sideways) by moving the toy to the side, helping him/ her to step sideways. Make sure to allow time for the child to play before moving the toy again, or frustration will result. For any of these activities, or for more suggestions, ask the child's physical therapist to provide you with further ideas.

Guidelines for Parents/Caregiver

It is very important for parents/ caregivers to be involved with their child's therapy program. The therapist may suggest exercises for stretching and/or strengthening, activities for play, and various positions for play, sleeping, and eating. Parents benefit from observing and/or participating in their child's physical therapy session. By being involved, parents will have opportunities to voice concerns, to learn home programs, and learn ways of interacting with their child to promote development. Parents spend more time with their child than therapists; therefore, they need to take an active role in their child's therapy program. Parents should feel comfortable asking their child's PT any questions. Likewise, therapists rely on parents to share information about how the child is performing at home. The parent, child, and therapist are all part of a team, and need to have open lines of communication.

Finding a Qualified Physiotherapist

Physical therapy may be provided in a variety of settings, including school, home, outpatient departments, preschool, and day-care centres. The physical therapist should specialize in paediatrics, as he/she will have better knowledge and understanding of development. Regardless, all recently graduated practicing PTs must have a masters or doctoral degree from an accredited university, have passed a national licensing examination, and be licensed to practice in their province. Physical therapy services may also be provided by a physical therapist assistant (PTA), under the direction and supervision of a licensed physical therapist. The PTA will have attended a two-year program and have passed an examination. The PT will do the initial assessment and formulate the treatment plan that the PTA will administer.

Physiotherapist and IEPs

The Individualized Education Plan (IEP) outlines the related services the child will receive, including annual goals and objectives. Physical therapy provided under the IEP must be educationally relevant, meaning that without the service, the child cannot participate fully in the educational environment. For example, children need to be able to sit in school. For a child with CdLS, this may be difficult due to low muscle tone and weak muscles and small stature. Therefore, the school PT may work on independent sitting, and provide an adaptive chair if needed. Physical therapy goals and objectives in the IEP must be functional and educationally relevant. During the child's IEP meeting, goals and objectives are discussed with the team, including the parent. It is during this discussion that parents should bring up any questions or concerns relating to PT goals and objectives. Additionally, the level of service is determined at the IEP meeting, based on the child's needs. Sometimes, physical therapy services are denied. In this case, parents should question the reason. Often the reason PT is denied is because the service is not educationally relevant. This does not mean that the child does not need PT; rather, it means that the child is functioning in the education environment, but may benefit from physical therapy under the medical model (outpatient services). These are usually provided through a children's rehabilitation hospital or a similar setting where the Early Intervention Services are provided. If services are denied and the parent feels that physical therapy IS educationally relevant, then a physical therapy evaluation should be requested.

Chapter 21 - Occupational Therapy & Sensory Integration

By Milagros J. Cordero, Ed.D., OTR/L, BCP

Occupational therapy (OT) is both an art and a science. It is defined as a profession that provides skilled intervention or treatment that helps an individual to develop, regain or maintain skills needed to participate in all aspects of life in a meaningful and satisfying way. Some people may think that OT is only for adults; after all, children do not have "occupations." However, a child's main job is playing and learning, and occupational therapists can evaluate children's skills for playing, school performance and daily activities and compare them with what is developmentally appropriate for that age group. OT is provided by a licensed occupational therapist, in many systems occupational assistants will perform many of the services prescribed by the licensed occupational therapist. The occupational therapist will look at the physical needs of the child; the function of his/her upper extremities, the individual's muscle control, posture, breathing pattern and suck and swallow skills.

Developmental milestones are also examined such as; ability of the child to bring the extremities to the mid-line and hands to the mouth, rolling over, following a moving object, crawling, moving from crawling to independent sitting, standing and walking. The term sensory integration is used to explain what happens to our body when all senses work together,

producing a picture of who we are, where are and what is happening around us. Sensory integration involves how a child receives information from the environment.

- Are the senses ready to be stimulated and alerted? How does the child understand this input?
- Will the child be able to use this information to modify behaviour?
- Is the child able to maintain a self- regulated state so that they can play, or will they be difficult to calm?
- Can they motor plan their moves(which is the ability of the brain to conceive, organize and carry out a sequence of unfamiliar actions), so they are efficient and accurate in their moves?

When a child with CdLS already experiences difficulties in receiving information from the environment such as touching objects, moving in space, hearing sounds and/or alerting to noises, gathering distorted information through their visual system, they will more likely experience dysfunction in sensory integration. For example, if a child has difficulty with meeting his arms or hands at midline and holding his head up, the occupational therapist will identify a sitting arrangement for the hands to come to midline to play and prepare him/her to feed him/herself and write. A therapy ball may be beneficial for someone to get the feeling of moving in space and develop upper body strength. If a child with CdLS has limb abnormalities, an occupational therapist will assist in adaptations of equipment so that the individual can participate in all aspects of life in a meaningful and satisfying way. Following an occupational evaluation, goals and objectives will be included in the early intervention, educational or service plan as needed. Occupational therapy assessment and intervention should focus on:

- Activities of daily living (caring for self-needs such as eating, dressing and toilet habits)
- Education (achieving in the learning environment) Play (appropriate toys, games, equipment and activities)
- Social participation (developing appropriate relationships and engaging in behaviour that doesn't interfere with learning or social relationships)
- Work (developing interests and skills necessary for transition to community life after graduation)

Occupational Therapist Might:

• help kids work on fine motor skills so they can grasp and release toys and develop good handwriting skills address hand-eye coordination to improve kids' play skills (hitting a target, batting a ball, copying from a blackboard, etc.);

- help kids with severe developmental delays learn basic tasks (such as bathing, getting dressed, brushing their teeth, and feeding themselves);

- help kids with behavioural disorders learn anger-management techniques (i.e., instead of hitting others or acting out, using positive ways to deal with anger, such as writing about feelings or participating in a physical activity);

- teach kids with physical disabilities the coordination skills needed to feed themselves, use a computer, or increase the speed and legibility of their handwriting;

• evaluate a child's need for specialized equipment, such as wheelchairs, splints, bathing equipment, dressing devices, or communication aids; and

- work with kids who have sensory and attentional issues to improve focus and social skills.

How PT and OT Differ

Although both physical and occupational therapy help improve kids' quality of life, there are differences. Physical therapy (PT) deals with pain, strength, joint range of motion, endurance, and gross motor functioning. OT deals more with fine motor skills, visual- perceptual skills, cognitive skills, and sensory-processing deficits.

Occupational Therapists Might

There are two professional levels of occupational practice — occupational therapist (OT) and occupational therapist assistant (OTA). Occupational therapists work in a variety of settings, including hospitals, schools, rehabilitation centres, mental health facilities, private practices, and nursing homes. Occupational therapy can help students succeed in academic performance and social participation. Occupational therapy practitioners use their unique expertise to help children with and without disabilities be prepared for and perform important learning and school-related activities to fulfill their roles as students. In the school setting, occupational therapy practitioners support academic and non-academic outcomes, including social skills, math, reading, writing, recess, participation in sports, self- help skills, prevocational or vocational participation, and more. They are particularly skilled in facilitating access
to curricular and extra-curricular activities for all students through support, design planning, promoting healthy routines, and other methods. The goal is for students to build upon their strengths while developing academic and social skills necessary for future independent living.

Chapter 22 - Complimentary Therapies

Most children with CdLS will participate in speech, occupational and/or physical therapies at some point to aid in their development. Over the years, families have explored a variety of additional therapies that further engage their children in activities that enrich their quality of life. Families have reported positive results as their children develop important skills, all while having fun. Each child is different and not all therapies may be of benefit to every child.

Before making the personal decision to enroll a child in one of these therapies, please consider the following questions:

- What objectives would I like my child to achieve as a result of this therapy?
- Does the therapist have experience working with children with CdLS or other disabilities?
- What are the therapist's qualifications and professional affiliations?
- What is the program's staff-to-child ratio?
- What safety procedures will be in place during the session? What are the physical demands of this therapy?
- Are parents encouraged to be present for the session? Do I feel comfortable with the level of supervision?

Complimentary Therapy Resources

Art Therapy https://www.canadianarttherapy.org/

Dolphin Assisted Therapy www.aquathought.com or www.dolphin-inspirations.com

Hippotherapy (horses) https://www.cantra.ca/en/services/hippotherapy

Music Therapy https://www.musictherapy.ca/about-camt-music-therapy/about-music-therapy/

Pet Therapy www.cci.org

Sensory Integration Therapy www.snoezeleninfo.com/escambia.asp

Therapy Camps http://nichcy.org/publications/camps

Rebound therapy (using a rebounder/trampoline) https://therabounce.com/practitioners

Chapter 23 - Transition into Adulthood

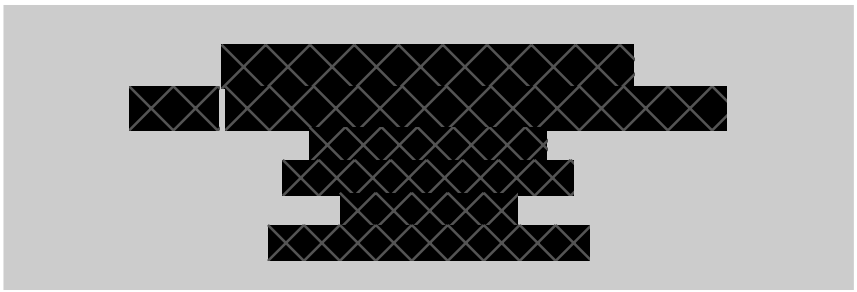
By Janette Peracchio, M.Ed., CdLS Foundation Family Service Coordinator (retired)

"Where do we begin?" is what I hear from parents when their child with CdLS reaches his/her teen years. When asked what their plans are for their child after high school, they often say they want the same type of life for their loved ones with CdLS as any typical young adult. This includes working or volunteering, spending times with friends and having a safe and happy life. However, most parents and guardians are at a loss for how to make these plans happen. Every student in a public education program has the right to a transition plan made at the Individual Education Program (IEP) meeting when they turn 16 years old. This should be updated at least once annually. If the child is able, they may be present at each IEP meeting to make choices about future plans. There are several programs used by schools and agencies to guide individuals and families during this important planning. Sometimes a teacher or an agency worker leads the group through the planning; other groups hire a facilitator familiar with the planning tool. The planning tools may have different names, such as McGill Action Planning System (MAPS), COACH or Person- Centred Planning, but they all have the same vision: to plan for the family and young adult's future by building partnerships and supporting choices. The planning stage can include several components for discussion: further education or training programs, long-term care plans, transportation, health care, safety, recreation, financial need, who is in the circle of support, companionship and having a purposeful life.

Several options for vocational colleges exist for individuals with intellectual and/or physical disabilities, many have criteria and they do come at a cost. If you have started an Registered Education Savings Plan for your child for example, you can comet together in your community with others to request a particular course to be created for your child with CdLS by using those funds.

Day programs and work programs do exist and many individuals with CdLS with a mild intellectual disability have shared with us that they do work. For example, a paper route, Winners, local daycare, Canadian Tire, physiotherapy clinic, hair salon and many others have been employers of individuals with CdLS in Canada. There are also options for group work placements for example, employment at a centre where they take in local businesses to provide with intermittent work opportunities like putting together documents, filling orders etc. Some have shared starting a soap making business, selling at local markets and events and bringing in others in their community with intellectual disabilities that are also seeking valuable participation/employment in the community..

Appendix 1- Sample Psycho-educational Assessment of a 10 year old with CdLS (used with permission by family and has been redacted)



[redacted]

D.O.B.: [redacted]

[redacted]

CONFIDENTIAL

PSYCHOLOGICAL ASSESSMENT REPORT

December 11, 20[redacted]

Reason For Referral:

[redacted]'s a 10 year-old girl with a complex medical presentation including diagnoses of Cornelia de Lange syndrome, epilepsy, oral-motor apraxia and a history of global developmental delay. She was referred for an updated psycho-educational assessment by Dr. [redacted] to assist with school programming and planning.

Relevant Background Information

[redacted] has been followed at [redacted] since she was six years old and details regarding her birth history and earlier development are well-documented in previous reports. She was seen most recently by Dr. [redacted] in the Pediatric Development Follow-up Clinic in May 2017. Updated information regarding [redacted]' current functioning was obtained from an interview with her mother, as well as from a review of previous medical and school reports.

Physically, [redacted]'s motor functioning is reasonably well-developed. She is able to run, jump and ride a bicycle. In terms of fine motor coordination, she is right-handed and can hold a pencil, although her printing is immature. With respect to her health, she continues to experience tonic-clonic seizures approximately once every three months. Her mother has recently switched to a different neurologist, Dr. [redacted], and [redacted] is now on a combination of Epival and Lamotrigine. She is also on a modified ketogenic diet, and has shown improvement in her focusing and energy level. Her health is otherwise good.

[redacted] also has a history of language delays and has been diagnosed with apraxia. She has received speech therapy since she was 2½ years old, most recently with [redacted] from [redacted] in 2016. Her last formal language assessment was conducted by Ms. [redacted] in November 2015 through the school-board. Ms. [redacted] noted that [redacted]'s attention had been short so the assessment had to be broken into several short sessions. [redacted] also needed information to be repeated, simplified, and supported with visual and concrete materials. Results indicated severe delays in both expressive and receptive language, with [redacted]'s standard scores falling below the 1st percentile. Her receptive skills were estimated to fall around an early to mid four year old level, considerably below her chronological age at the time (8 years, 10 months). Expressively, [redacted] was described as an "intentional multi-modal communicator". She used a variety of verbal and nonverbal means to communicate including short phrases, gestures and facial expressions. Her social communication skills were appropriate with respect to joint attention, eye contact, and initiating communication. In addition to her language, [redacted]'s basic numeracy and literacy skills were also assessed by Ms. [redacted] Results indicated that she was at the kindergarten level functionally. Specifically, she was able to recognize letters but was not yet identifying sounds or sight words.

With respect to her education, [redacted] previously attended a [redacted] private school when the family lived in [redacted]. When she moved to [redacted] she transferred to [redacted] School. As her early schooling was not in a traditional program, she was held back a grade compared to her chronological peers. Although she has not been through the IPRC process, she has an Individual Education Plan (IEP) and is on a modified program for all subjects. Strategies to address her learning needs include direct instruction, concrete materials, high structure, rephrasing instructions, and access to a scribe. [redacted]'s attentional difficulties are also addressed through the use of frequent breaks and strategic seating. Since Grade 2 she has been in the Home School Program, where she spends the mornings in a small special education class, and the afternoons in a regular class. She is currently in Grade 4.

Despite the extra support she receives at school, [redacted] has made very slow academic progress. According to her progress report card from November, she is still working on blending sounds, although she has developed a few sight words at least. At home her mother notes that [redacted] loves being read to, but she is not sure how much [redacted] understands the story. [redacted]'s math skills are estimated to be at the junior kindergarten level. She is showing better one-to-one correspondence in counting but is still very much at a concrete level.

[redacted]'s parents also note that her social skills and interests seem to be at a younger level. She has recently started showing an interest in Dora the Explorer, for example, and likes activities such as painting, colouring and imaginative role-playing. She does have friends and is well-liked by her peers, but her friends tend to "mother" her and help her out at school. She has a friend in her HSP class who also has special needs, whom she plays with at recess. She also has play-dates at her house.

Previous Testing

[redacted] was initially seen for a psycho-educational assessment at [redacted] by Ms. [redacted] in December 2013 when [redacted] was seven years old. [redacted]'s attention span was short during the testing, and she had difficulty understanding some task instructions. Testing with the *Wechsler Preschool and Primary Scales of Intelligence: 3rd edition* revealed below skills overall, with her Full-scale IQ falling below the 1st percentile. Although she demonstrated some relative strengths in certain nonverbal tasks, both her Nonverbal and Verbal IQ scores fell below average overall. [redacted] had somewhat better success on a supplemental nonverbal test (the *Leiter)* where there were no verbal instructions. However, her overall skills again fell below the average range for her age (19th percentile). [redacted]'s academic readiness skills also fell well below average based on her responses to the *Bracken Basic Concept Scale*. In contrast, her adaptive skills were more variable, with relative strengths noted in Daily Living Skills and Socialization (low average range), compared to her Communication skills (well below average).

Behavioural Observations

[redacted] was seen for a cognitive assessment that took place across two sessions, on November 27, and December 6, 2017. [redacted] separated from her mother without difficulty. She presented as a very pleasant and cooperative girl who easily established comfort and rapport with the examiner. Although [redacted] sat nicely and remained at the table, she demonstrated an impulsive approach at times, and needed reminders to look at all items on the page before pointing to her answer. [redacted] also often needed encouragement to approach a task that she appeared to find more challenging. At times she would simply respond with "Hard", but then she was often willing able to attempt the task with encouragement. [redacted]

attended well to all activities presented in the one-to-one setting, and was able to work through tasks without requiring redirection.

In terms of language, [redacted] spoke in single words and short phrases. Her articulation was at times unclear, but intelligibility was usually good within context. She used many gestures to enhance her communication, and she often attempted to gesture instead of providing a verbal response. Receptively, she appeared to have difficulty understanding some verbal instructions on tasks, but repetition and simplification of instructions were provided when possible.

Overall, given her cooperation and attention, the present results are seen as a valid estimate of [redacted]'s current level of cognitive functioning.

Assessment Results

Cognitive Ability

The *Wechsler Intelligence Test for Children – Fifth Edition* (WISC-V) was used to assess [redacted]'s general cognitive abilities. The WISC-V is a standardized test that assesses both verbal and perceptual (i.e., non-verbal) reasoning ability using a variety of tasks, including answering questions, defining words, and working with blocks and pictures.

Consistent with previous testing, [redacted] again had great difficulty with the tasks from the WISC-V, with her Full-scale IQ now falling below the 0.1 percentile. Her performance was consistent across all indices with index scores falling at or below the 1st percentile. There was no difference in her performance on verbally-based compared to nonverbal tasks. In both areas, demonstrated skills were consistent with functioning at or below the six year age level. In general, [redacted] was able to complete items requiring concrete skills such as matching or copying, but had more difficulty when asked to apply reasoning to figure out or problem-solve an answer. For example, when asked to complete patterns, or compare pictures, she was able to match or sequence based on *one* attribute (e.g. colour or shape) but had difficulty when asked to integrate more than one attribute in her decision-making. This observation is consistent with comments on her report card.

Given her oral language difficulties, [redacted] was also given the *Comprehensive Test of Nonverbal Intelligence: 2nd edition* (CTONI-2). Unlike the WISC-V this test has no verbal tasks, thus all the information is presented visually in a multiple-choice format. As [redacted] only had to point to indicate her response, the test placed no demands on oral or written language. As on the WISC-V, [redacted] generally had success on the first few items of each subtest, where the information was based on simple matching or picture association (e.g. things that "go together" in everyday life). She began to struggle as soon as the tasks required her to apply more abstract thinking, and her final score fell below average, below the 1st percentile. She demonstrated a relative strength in a task assessing geometric categories (comparing shapes) where she performed at the 7½ year level. In contrast, her performance on the remaining tasks fell below the six year level, consistent with her functioning on the WISC-V.

Receptive Vocabulary:

[redacted]'s receptive vocabulary skills were assessed using the *Peabody Picture Vocabulary Test: 4th edition* (PPVT-IVA). This is another picture-based multiple-choice task where individuals are asked to point to one of four pictures which best represents a word. [redacted]'s score fell at the 0.2 percentile for her age,

which represents functioning around the early 5 year level. It is interesting to note that [redacted] performed at an early 4 year age equivalent when she was administered this same test two years ago on her speech and language assessment. This indicates that [redacted] has shown measurable improvement in her receptive vocabulary over the past two years, although her progress has been slow.

Memory Ability

[redacted]'s memory skills were assessed using the working memory tasks from the WISC-V, as well as selected subtests from the *Wide-range Assessment of Memory and Learning: 2nd edition* (WRAML2). The WRAML-2 is a standardized assessment tool used to measure visual and auditory/verbal memory through a variety of tasks. Consistent with her cognitive abilities, [redacted]s memory abilities are also generally weak, although she does demonstrate an area of relative strength. Specifically, she did quite well when asked to remember visual information presented within a *meaningful* context (i.e. pictures). Her score fell at the 75th percentile. In contrast she showed very poor recall for visual information that was less meaningful (i.e. *spatial* information: 1st percentile).

[redacted] also had difficulty recalling information presented in an *auditory* context, even if it was presented in short chunks over repetition. Her performance fluctuated, however, suggesting that she may have had difficulty sustaining her attention during the repeated trials. For example, when asked to learn a list of words presented multiple times, she initially appeared to benefit from the repetition and showed significantly better recall after the second trial, but then her recall deteriorated dramatically over the next two trials, which is highly unusual. Although her score fell below average (2nd percentile), it is interpreted cautiously and *is likely an underestimate of her memory abilities* in this area.

[redacted] also had great difficulty on a set of rote tasks sensitive to attention and concentration. On these tasks she was asked to repeat brief auditory and visual information. She had great trouble sustaining her attention beyond the first couple of items, and ultimately scored well below average at the 0.1 percentile. She also struggled on tasks involving *working memory*, which was assessed on the WISC-V. Working memory refers to the ability to hold information in mind while manipulating it. These tasks also included an auditory and visual component. On the auditory task [redacted] was asked to repeat a sequence of numbers forwards, and then backwards and in numerical sequence. On the visual working memory task she had to remember a series of pictures of increasing length. Both tasks were challenging for her, with her overall working memory index falling below the 0.1 percentile.

Academic Ability

[redacted]s academic achievement was assessed using selected subtests from the *Wechsler Individual Achievement Test: 3rd edition* (WIAT-III) and from the *Woodcock-Johnson Tests of Achievement: 3rd edition* (WJ-III). Her reading skills were assessed using the Early Reading skills subtest from the WIAT-III and the Letter-Word Identification from the WJ-III. Demonstrated skills fell at the kindergarten level for both tasks, consistent with comments from her report card. In terms of specific skills, she recognized most letters although she showed some confusion with lower case b's and d's. She could identify some sounds and a few sight words, but did not understand any questions involving phonological processing. Similarly, in the area of spelling, she could write her name and could print the letters to go with some sounds, but could not spell any of the words on the list.

[redacted]'s math skills fell at a similar level as she scored below the 0.1 percentile on both the Math Problem-solving and Numerical Operations subtests from the WIAT-III. In terms of skills observed, she was able to

identify and print numbers and showed one-to-one correspondence in counting. She was unable to complete any items involving adding, even with pictures.

Adaptive Functioning

[redacted]'s adaptive skills were evaluated using the *Adaptive Behaviour Assessment System: 3rd edition* (ABAS-III). The ABAS-III is a standardized questionnaire assessing information about a student's everyday skills around the classroom and school community. [redacted]'s mother and teacher were each asked to complete a form in order to obtain information about her adaptive functioning in different settings.

Consistent with previous testing, [redacted]'s adaptive skills again represented an area of relative strength for her as both her mother and teacher rated her functioning within the normal range in some areas. While her adaptive skills were highly variable, both her teacher and mother reported similar results. Indeed, [redacted]'s overall General Adaptive Composite score was the same for both raters, falling below average at the 3rd percentile. [redacted]'s scores were highest in the *Social* domain, though somewhat better in the home setting compared to the school setting (34th and 23rd percentile, respectively). Within the Social domain both respondents noted age-appropriate *social skills* with respect to behaviours such as being polite, demonstrating empathy, and apologizing when appropriate. Her *leisure skills* were also rated in the normal range on the parent form, but below average on the teacher form. Her teacher reported, for example, that [redacted] does not always participate in organized activities with her peers, and is less likely to initiate activities with others. This is not surprising given her speech difficulties.

[redacted] also demonstrated a relative strength in the sub-domain of *Health and Safety*, which falls within the *Practical* domain. While her overall domain score fell below average on both forms (4th and 5th percentile), she was rated in the Average range for Health and Safety skills on the teacher form. Her teacher noted that [redacted] is a responsible student who follows safety rules appropriately both at school, on the playground and on field trips. Her functioning within the other sub-domains assessing self-care, community use, and home/school living, is less-developed, and fell consistently below average for her age.

In contrast to her relative strengths in the above areas, [redacted]'s scores on the *Conceptual* domain fell well below average, below the 1st percentile for both the parent and teacher forms. This domain captures information about her communication, functional academic skills and self-direction. Given her cognitive limitations it is not surprising that this is her weakest area of adaptive functioning.

Summary/Formulation:

Although [redacted] has made gains in most areas since her last assessment, her progress has been slow and the gap has now widened between her and her peers. It is important to note that her cognitive skills are limited *even when her speech and motor impairments are taken into account*. [redacted]'s memory skills are also weak overall, although she does demonstrate a relative strength in picture memory. Her poor memory skills are likely contributing to her academic struggles. Consistent with her cognitive limitations, [redacted] is also functioning below average in most aspects of adaptive functioning, especially the conceptual domain which assesses skills such as communication, functional academics, and self-direction. In contrast, she demonstrates relative strengths in the aspects of adaptive functioning that are less sensitive to cognitive ability, including her social skills and health and safety skills.

While [redacted] presents with a number of relative strengths, given the extent of her delays in cognitive, academic and most adaptive areas, despite the considerable support she has received to date, she now meets criteria for a diagnosis of **Intellectual Disability**. Her current skills are estimated to fall within the **mild range**. While she will continue to make progress, it will be at a much slower rate than her peers.

[redacted] also exhibits attention difficulties including distractibility and a short attention span. As these issues were not formally assessed, it is difficult to know whether these issues are part of a separate clinical disorder, or best understood within the context of her cognitive disability, and her seizure disorder. Nevertheless, her attention difficulties are likely impacting on her academic functioning and will need to be addressed.

Recommendations

Given the results of this assessment, the following recommendations are offered to help meet [redacted]'s needs:

- Given her cognitive limitations, [redacted] will require a modified curriculum and considerable support at school. She will benefit from a small class placement that offers a slower pace to teaching academics, and a life-skills component. However, given her relative strengths in social functioning, it will be important for her to continue to have regular access to typically developing peers who can function as good role models for her. Indeed, her parents find that [redacted] does not cope well when she is around children with unpredictable behaviour, which can often in students with significant cognitive limitations. Given the challenges in finding an appropriate placement for her, it is recommended that these results be shared with the Student Support Team for her home school, so that [redacted]'s needs may be identified.

- [redacted] will require new information to be broken up into short pieces, and presented at a slower pace, in a multi-sensory format. When teaching new concepts emphasize concrete materials and make the information as meaningful as possible by relating it to everyday living and by using motivating materials. [redacted] will also require considerable rote repetition of concepts and will need help in transferring previously acquired skills to new situations.

- Verbal instructions should be simplified and accompanied by visual cues as much as possible. Repeat instructions and allow additional time for [redacted] to respond to a verbal request. Whenever possible provide a visual model or demonstration of a concept.

- Additional strategies to address [redacted]'s language and learning needs are available in the TDSB speech and language report dated November 2015.

- Given her cognitive limitations, [redacted] will require a functional approach to math that focuses on the knowledge of basic operations within the context of real-life situations, such as going to the grocery store, measuring amounts of ingredients for a recipe, etc. Teach her to use a calculator, for example, and to use it when shopping. [redacted] should also be encouraged to gain a good understanding of time and money, as these are important skills to have as she becomes more independent.

- Memory testing indicates that [redacted] will remember visual information best when it is presented in a meaningful format such as pictures. Verbal information should be broken into small chunks and

offered through extensive repetition to improve her likelihood of recall. [redacted] may also benefit from being taught mnemonic strategies to facilitate her recall of material. *The Memory Book* (Lorayne and Lucas) is an excellent resource in this regard.

- [redacted]'s attentional difficulties will also need to be addressed. It will be important to teach her in short bursts of structured lessons, with frequent breaks built into her schedule. Continue to offer strategic seating and to minimize distractions as much as possible. [redacted] will need frequent reminders to work carefully as well as redirection to help her stay on task.

- Building friendships and social relationships will become increasingly important for [redacted]. Her parents may wish to access programs and resources through agencies such as Community Living, which will allow her to meet new people with challenges similar to her own.

- Continue to encourage [redacted] develop as much independence as possible in activities of daily living such as hygiene and household chores. In this regard, her parents are encouraged to read the book *Steps to Independence: Teaching Everyday Skills to Children with Special Needs. 4th Edition*. Bruce Baker & Alan Brightman, (available from Parent Books, 416-537-8334).

The above information was shared with [redacted]'s parents in a feedback interview on December 11, 2017.

[redacted], Ph.D. C.Psych.
Child Development Program

Electronically Signed by: [redacted] Psych
Electronically Signed: [redacted]
Transcribed by: [redacted]
Dictation Date: [redacted]
Transcription date: [redacted]
Report Status: [redacted]
Report Number: [redacted]

Appendix 2: Sample IEP Goals

It is important to remember that each goal should have objectives and actions that the school staff can use to support the student in achieving these goals. Simply choosing the goal and writing it correctly will not ensure achievement. Each goal has to have appropriate actions that are assigned to an individual to be accountable for as well as based on rational and evidence to support the achievement of the specific goal.

Elopement

Sample Elopement IEP Goals

When creating Individualized Education Program (IEP) goals for autism elopement (the tendency to wander or run away), it's important to focus on safety, communication, social skills, and coping strategies.

Here are 10 sample IEP goals for elopement:

1. Safety Awareness: By [date], when prompted, [student] will demonstrate understanding of personal safety rules related to elopement (e.g., staying with designated adults, not leaving school grounds without permission) in [percentage] of opportunities.
2. Communication Skills: By [date], [student] will use a predetermined communication system (e.g., picture exchange system, verbal communication) to express basic needs and desires instead of engaging in elopement behaviour in [percentage] of opportunities.
3. Social Skills: By [date], [student] will engage in parallel or cooperative play with peers for [duration] minutes without attempting to elope in [percentage] of structured social situations.
4. Self-Regulation: By [date], when feeling overwhelmed or anxious, [student] will independently request a break or use a calming strategy (e.g., deep breathing, fidget toy) instead of attempting to elope in [percentage] of observed instances.
5. Response to Cues: By [date], [student] will appropriately respond to visual or verbal cues from adults indicating the need to stay in a specific area or follow a specific direction in [percentage] of opportunities.
6. Environmental Awareness: By [date], [student] will demonstrate understanding of safe and unsafe environments by identifying and avoiding potential hazards (e.g., roadways, bodies of water) without adult prompting in [percentage] of opportunities.
7. Functional Communication: By [date], [student] will use at least [number] functional words or phrases related to safety and elopement prevention (e.g., "stop," "stay with teacher") in daily interactions with adults and peers.
8. Cognitive Skills: By [date], [student] will follow multi-step instructions related to staying in a designated area or returning to a supervised location without attempting to elope in [percentage] of opportunities.
9. Peer Interaction: By [date], [student] will initiate and sustain interactions with peers during structured activities without attempting to elope for [duration] minutes in [percentage] of opportunities.
10. Family Involvement: By [date], [student]'s family will implement strategies and safety measures outlined in the IEP to reinforce skills related to elopement prevention at home and in community settings as evidenced by [specific measure of progress or compliance].

These goals should be tailored to the individual needs, abilities, and preferences of the student, and should be regularly reviewed and adjusted as needed. Additionally, involving parents, caregivers, and other relevant stakeholders in the goal-setting process is essential for success.

List of Sample Behaviour Goals for an IEP

This is just part of a giant list. We like that some of these behaviour goals include work completion goals.

1. By the expiration date of this IEP, _____ will manage conflicts, independent of teacher support in 4 of 5 observed occurrences over a 2-month period as measured by observations and performance assessments.
2. By the expiration date of this IEP, given a self-monitoring checklist, _____ will demonstrate self-regulation during 90% of weekly sessions as measured by observations across 2 months.
3. By the expiration of this IEP, given a writing assignment, _____ will initiate his work as evidenced by beginning to write letters on his paper within 1 minute of the assignment being presented in 80% of a minimum of 20 recorded opportunities over a period of 2 months, as measured by observation and performance assessments.
4. Throughout the school environment while using a five-piece token board with a visual of his rules (follow directions and have a safe body) listed at the top, _____ will follow both of his rules (follow directions and have a safe body) to earn all five of his tokens for each half-hour period, in group and 1:1 academic sessions, in 80% of trials probed in 4/5 observations for at least a 2 month period before the expiration of this IEP, as measured by observations and performance assessments.
5. _____ will request (using his/her communication method) and take a break when he needs one, and return back to a task after a break independently in 8 out 10 opportunities over a minimum of two months, as measured by observations and performance assessment by the expiration date of this IEP.

Adaptive Behaviour IEP Goals

Here are some examples of IEP goals for adaptive behaviour or behaviour goals examples:

1. Goal: Improve self-care skills.
    - Objective 1: The student will independently perform personal hygiene routines, such as brushing teeth and combing hair, with minimal verbal prompts.
    - Objective 2: The student will develop the ability to dress and undress independently, including fastening buttons, zippers, and shoelaces.
2. Goal: Enhance social skills and peer interactions.
    - Objective 1: The student will initiate and maintain simple conversations with peers, using appropriate greetings and turn-taking, in at least two different social situations.
    - Objective 2: The student will demonstrate an understanding of personal space by maintaining an appropriate distance when interacting with others.
3. Goal: Develop functional communication skills.
    - Objective 1: The student will use augmentative and alternative communication (AAC) system effectively to make basic requests (e.g., asking for a drink, indicating discomfort) across different settings.
    - Objective 2: The student will expand their vocabulary and expressive language skills by learning and using new words and phrases in daily conversations.
4. Goal: Improve independent living skills.
    - Objective 1: The student will demonstrate the ability to follow a daily routine independently, including organizing personal belongings, preparing a simple meal, and cleaning up afterward.
    - Objective 2: The student will learn and practice basic money skills, such as counting and making simple purchases, in real-life situations like a grocery store.
5. Goal: Develop problem-solving and decision-making skills.

- Objective 1: The student will identify problems in their environment and generate at least two appropriate solutions for each problem, with minimal prompts from a teacher or caregiver.
- Objective 2: The student will use a decision-making process (e.g., gathering information, considering options, weighing pros and cons) to make choices in different contexts, such as selecting a preferred leisure activity or deciding on a meal option.