Putting the Puzzle Together

UNDERSTANDING NEEDS AND MAKING INCLUSION WORK

2009 Published By:
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Coquitlam, BC V3K 7A1
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www.kansept.com

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FUNDING GRACIOUSLY
PROVIDED BY
THE HYDRECS FUND

PUBLISHED BY:
The Cerebral Palsy Association of BC
2009

A Message about Putting the Puzzle Together

It is done for now; yet will ever be a work in progress. As you can imagine, pulling together a work of this magnitude doesn't come without its challenges. Please take this project for what it is intended to be—a stepping stone to understanding some of the various health needs of students who may be in your classroom. For more in-depth information we encourage you to contact the individual associations listed at the back of this manual. They are the experts in their field.

For those of you with an eye to consistency in writing styles and formatting, please keep in mind the health conditions presented here were the result of more than 32 different writers, 29 of which were students of the Special Education Teacher Assistant Program at the Richmond Campus of Kwantlen University College. Each student's research project became part of this book. Trying to streamline so many different writing styles and layouts, into one consistent format for publishing, hasn't happened without a few bumps along the way. We are aware that our efforts to do this are not perfect, but they are the best that we can do, at the moment, under our time constraints.

Our hope is that the following pages may help in some small way to make your classroom a safe and welcoming place for everyone.

Cerebral Palsy Association of B.C.

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Specific Conditions Index

Purpose of Manual

The purpose of this handbook is to assist teachers in feeling more comfortable about including students with all abilities in their classrooms.

You will find information about the various disabling conditions—information you need right away, when you learn that you will be teaching a child who requires extra support.

The parents of your students are your greatest resource in discovering how to best work with their child. Included in this manual are suggestions on how to ensure the most effective cooperation between school and home.

Many children with physical disabilities have special equipment for mobility or communication. A section of this manual will explain some of these items and suggest how you can work with the student in using them.

Experiences of other teachers, who have made inclusion work for their students, can help you adapt your teaching style to challenges that are new to you. Adjusting the classroom space, adapting the curriculum, and teaching social behavior are some of the topics that you can learn from other professionals.

Helping all students accept their classmates is an important aspect of inclusion. You will find material, on the following pages, to help you with this.

You will also find help understanding the transitions your students will make through the years: preschool to kindergarten, elementary to secondary schools, and from there—making realistic plans for the future.

Contact information for other disability-related organizations, many of whom have libraries and other resource information that you will want to access, is found in the last section of this manual.

Photocopying and sharing the information in this handbook is encouraged. Please feel free to use the material on these pages in any way you wish

in order to facilitate the inclusion of all students into your classroom. We do ask that if you wish to produce this manual in its entirety that you contact us at the Cerebral Palsy Association of BC so that you can purchase a copy. Thank you. ~

Letter From a Parent/Advocate

Dear Teacher

Do you know what to say to a child in a wheelchair? How to communicate with a person who has a hearing impairment? Do you look away? Do you stare? Or do you do nothing at all out of the fear of doing the wrong thing and offending?

Every day of my life I cope with wheelchairs, braces and voice output computers . . . surgery, hospitalization and recovery. I cope with too many appointments, meetings and endless telephone calls. I probably should know how to react to any person with a difference—BUT I DON'T. Why is this? Curiosity—it is not a bad word or an undesirable trait. Our natural curiosity is aroused by the differences between us—and most people with differences, in my experience, are better at handling direct questions than they are at coping with the *stares* of people too polite to ask.

Children, on the other hand, can get away with a lot . . . occasionally a child will ask my son, "What's wrong with you? Why aren't you walking? Did you break your legs?" Their parent is often mortified and may try to stop the child. My son usually smiles, gives me the look that says, "It's o.k. mom" and either gets me or the computer to say, "I have cerebral palsy so the muscles in my legs don't work the same as yours." Cory's smile and answer break the ice and we proceed from there.

This manual is the result of feedback from families and teachers with concerns about the process of inclusion. By working through this resource you are taking an important step towards solving the puzzle of inclusion. This manual offers suggestions for implementing an inclusive approach that will help every child develop to their fullest potential. It embraces the team approach—sharing ideas and strategies of teachers, specialists and families.

Where do our values and ideas come from about those who are different than us? Think back to your first experience with someone who was different than you. This exercise may remind you of the loneliness of a childhood acquaintance who was isolated because of that difference—on the other hand, perhaps you had a positive relationship with someone with a difference—a high school friend or favourite aunt.

The following conversation was overheard at a parent/teacher workshop.

"We're getting an ADHD, a Downs, and a Leukemic next year."
"I wonder which will be the biggest challenge?"
"I guess we'll draw straws!"
"I guess the ADHD will be the hardest."
"Ya. I guess the Leukemic will be absent a lot."

The language we use to describe people's differences influences us more powerfully than we may realize. When one considers that language is a primary means of communicating attitudes, thoughts and feelings—the elimination of words and expressions that stereotype is an important task.

The English prefixes *in* and *dis* when applied to the words *valid*, *firm* and *abled* indicate the negative connotation towards perceived imperfection … *invalid*, *infirm* and *disabled*.

Many influences—historical, literary, and linguistic—shape our beliefs and directly influence our attitudes and behaviours toward those with a difference. The non-person approach is characterized by an apparent inability to acknowledge another's presence. It's also not uncommon for a person with a difference to be considered much younger than he really is and thus babied. Other common behaviours—*pats on the head* and *special favours* are condescending and do nothing to promote equality.

Some people seem to believe that *disabled* equals *dumb*. This is particularly problematic for people with communication disorders because their intelligence is often judged by their speech.

It makes all the difference in the world how you see us. If you see us as suffering victims, you will offer us charity, but not freedom. If you see us as resisters, you may offer us solidarity in our struggle for freedom.
—BISHOP TUTU

Our biggest hurdle may be fear of the unknown. We question our ability to relate to the child. Our anxiety over the disability itself causes us to focus on the 'differences' rather than the 'similarities' between us.

What does inclusion mean to you? Is it recognizing that we are *one* even though we are not the *same*? Is it ensuring that all support systems are available to those who need support?

The goal of inclusion is to prepare children to participate as full and contributing members of society. Inclusion means providing a "quality education system that assists in the development of human potential and improves the well-being of each individual person in British Columbia's society." (Year 2000 mission statement, Ministry of Education) Putting these philosophical ideals into practice with real children has challenged teachers striving to meet the needs of every child in the classroom.

> *Everything can be taken away but one thing . . . to choose one's attitude in any given set of circumstances.*
> *—VICTOR FRANKL about life in a German concentration camp.*

Everyone plays an important role in inclusion. After working through this manual, our hope would be that we might hear the conversation quoted earlier reworded to facilitate the kind of individualized support necessary for every child to be an active learner.

> *"We're getting students with Attention Deficit Disorder, Down Syndrome and Leukemia next year."*
> *"I wonder which will challenge my abilities most?"*
> *"I guess the child with Attention Deficit Hyperactivity Disorder will challenge my experience the most."*
> *"I need to learn more about Leukemia."*

Yours sincerely,
Laurie Fisher

The First Day of School

By Janneane Randall

Today is the first day of school. My son, Andy, is entering the first grade. He gets on the bus as if this were any other day. But I know that today is very special. I am excited for him and very nervous. I want him to like his new school and his teachers. I want him to be accepted and to make new friends. On this first day of school, I have the same hopes as all parents. But my fears are different—as different as my son.

When Andy was very young, my husband and I knew that something was wrong. His language was not developing appropriately, and his behavior was *not quite right*. After many evaluations Andy was diagnosed with autism.

Andy spent three years at a wonderful *special* school. He learned to make friends with the children in his class because social skills were a part of every child's *individual education plan*. In a world where being the same as everyone else is so important, his school was a safe haven. There he was the same as everyone else. No one stared when he made funny noises or flicked his fingers in front of his eyes. No one thought it strange that he could not communicate like other children his age.

On his last day at that school, I walked him around the classroom to shake hands and say goodbye. Some children wished him luck; others wanted to know if his new school was very big or it he was scared. Each of his teachers gave him big hugs and kisses. Everyone told me how much they would miss him. Some of the teachers cried as they said goodbye. I cried, too.

Today is the first day of school. It is time to move on, time to give inclusion a chance. Other parents who have done this tell me that even though it is not easy, it is the right thing to do. I try to believe this, but there are

times when I have my doubts. A good and wise friend tells me that if I wait for Andy to become more normal before sending him to regular school, I will be waiting forever. I know she is right. It is unfair to Andy to keep him sheltered in a special school forever. I know that he will have to face the real world someday, but in my heart, I long to have him back in that safe place.

Andy's sister, Allison, is worried too. She is 10 years old—a self-conscious age when everything is a potential embarrassment. She is afraid the other kids at school will think that her brother is 'weird'. She worries they will call him names. She worries they will make fun of her too. I can't promise that her worst fears will not be realized. I tell her if kids tease it is because they don't know any better. Allison considers that small consolation.

Today is the first day of school. How will Andy cope with this new world? For the first time ever, he will have recess, library time, music class and lunch in a cafeteria. He will be one in a class of 30 instead of eight. When he gets confused or upset, I hope he will not bite his hand a scream, "No!" like he does at home. I know this hope is unrealistic.

Today is the first day of school. I will worry, hope, pray and dream. I want this to work; I want this more than anything I have ever wanted before. I want Andy to be happy. I want him to make a friend. I want people to see him for what he is—another child, just like all the others.

HARD WORK PAYS OFF

Andy's first year in public school was ultimately successful, but it was a success born of great challenges, teamwork and a willingness to try new ideas. Initially, Andy had a hard time adjusting to this new and often overwhelming environment. He responded by having tantrums and biting himself. Fortunately his teachers and the special education director were willing to be creative. Andy's sensory integration therapist came into school to train his teachers and his aide. An inclusion specialist helped everyone work more effectively with Andy, and helped them understand the reasons for his problems.

By mid-year Andy was doing well in school and seemed happy. He was interacting with the other children, making friends and getting invited to birthday parties.

This past year wasn't an easy one but we accomplished something important. Andy became the first child with autism to be included in a regular classroom in our town's public schools. Now second grade is just around the corner. This year, I face the first day of school without the doubts and fears of last fall. Andy has proven that with the proper supports, he can succeed in public school.

⁂

Jan and her husband, Bob, live in Seekonk, Massachusetts with their daughter Allison, and son Andy. Jan started a support group for mothers of children with autism. She works at Community Autism Resources, a public service agency.

—From: *Exceptional Parent*, September, 1994

Section 1

Inclusion For Today's Schools

Inclusion/Integration

INCLUSION

Describes the principle that all students are entitled to equitable access to learning, achievement and the pursuit of excellence in all aspects of their education. The practice of inclusion is not necessarily synonymous with integration and goes beyond placement to include meaningful participation and the promotion of interaction with others.

INTEGRATION

Is one of the major strategies used to achieve inclusion. With integration, students with special needs are included in educational settings with their peers who do not have special needs, and provided with the necessary accommodations determined on an individual basis, to enable them to be successful there. The principle of *placement in the most enabling learning environment* applies when decisions are made about the extent to which an individual student is placed in regular classrooms, or assigned to an alternate placement.

—BC MINISTRY OF EDUCATION: *Special Education Services: A Manual of Policies, Procedures & Guidelines*

Introduction

All students should have equitable access to learning, opportunities for achievement and the pursuit of excellence in all aspects of their educational programs.

—BC MINISTRY OF EDUCATION: *Special Education Website* 2006

Portions of this resource book are the result of a large research project conducted by the people listed below while some of them were students at the Richmond campus of Kwantlen University College, training to be special education teacher assistants in the SETA Program.

They framed the questions that most educators have when they work with students that have special needs, and researched the most up-to-date information to provide answers. Since the intent of the resource book is to provide a starting point of knowledge and understanding, they also included additional sources of information in the bibliographies of their research projects, enabling readers to pursue further information with more ease.

Many of the students also created stories called *A Day in the Life*, assuming the role of the person with the need, to further illustrate the impact of the particular condition on the daily life of a student. Many of these stories were based on interviews with real people, and some were written by parents and siblings, and are indeed true stories. To protect the privacy of individuals, the true stories and the fictional accounts have not been differentiated except for one which was written by a student who is also the mother of a girl with autism, and the introductory story at the very beginning of the resource book, which was written by Tammy van der Kamp Tammy is an

adult living with CP, and is a family and individual support worker with the CP Association.

Ulla Martin
Retired Instructor
Introduction to Diversity in the Classroom
SETA program
Kwantlen University College

The following people contributed some of the information and stories that make up this binder, with the hope that it will enable all educators working with students who have special needs:

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Sandeep Dhillon
Robyn Doornberg
Melissa Eisbrenner
Chrissy Furnell
Elizabeth Gooden
Somar Grewal
Holly Haughian
Wendy Hawryzki
Rachel Ho
Darlene Jewra
Jared Klassen
Grace Li
Cathy McAusland
Rose McGee
Emily McKinnon
Jennifer McQueen
Michelle Metheral
Chris Neufeld
Karina Ott von Wall
Kathy Porter
Jasmin Randhawa
Anne Renaud
Shaila Santos
Robyn Scott
Tracey Todd
Trinity Tucker
Bruce Withers
Kimberley Yoshihara

A special thank you to Tammy van der Kamp for providing her personal account of what it is like to grow up and live with cerebral palsy. Also, a special thank you to Wendy Hawryzki, Office Administrative Assistant of the Cerebral Palsy Association, for her dedication, expertise and editorial assistance in this project.

A Day in My Life

by Tammy Tammy van der Kamp

Inclusion has come a long way. I attended an elementary school in BC in the early 1970's as a ward of the Province. At that time, inclusion meant the public school system, but a separate classroom and curriculum. All the children with a recognizable disability were in the same classroom. At recess we segregated ourselves. It was a BIG deal when early in grade five, I was finally admitted to the *regular* classroom. My peers had been prepared for my arrival by a well-meaning system and teacher that failed to take into account my feelings as the *object* of discussion. I wasn't present, so there was no initial opportunity for my classmates to ask me questions about my disability. There was no attempt at real ice-breaking back then, though the teacher tried very hard to make me feel welcome. Still, I had to deal with some teasing and bullying, both subtle and obvious. The other disabled kids bugged me because I was in a *regular* classroom, therefore I must be the teacher's pet. And the able-bodied kids only associated with me when they needed my help in class; they wouldn't have anything to do with me in the hallways or at recess. I wasn't the kid that got invited to all the parties.

I was also the only kid confined to the school property during lunch and recess. The rest of the school could head to McDonald's or the 7-Eleven, but due to liability issues, I had to stay on the school grounds, constantly dogged by my adult attendant. How embarrassing for a kid, especially during the sensitive preteen and adolescent years, to have the ball-and-chain attendant that had to accompany me to class, and even the bathroom! My loving foster-family provided a stable home environment, but I was still insecure and anxiety-ridden to the point that my social competence was hampered.

On one hand, I really wanted the chance to do my own thing in order to

gain some confidence and self-esteem; on the other hand, there was a fear of the vulnerability that came with being alone. I didn't have much experience being alone. What would I do in an emergency? All in all, my school experiences, both good and bad, helped equip me for adult life, particularly my role as a Family & Individual Support Worker.

MORNING

I'm usually awake by 7:00 AM, but my day typically begins at nine; so I have a couple of hours to distract myself from thinking about my full bladder. I do that by planning my day: are all of my arrangements in place? Transportation, meals, bathroom breaks, cell phone charged, water available, the list seems endless sometimes, but the day's accoutrements all need to be ready, and it's my responsibility to see that they are. I don't need a full two hours to mentally line up my day, and that's where Rocket, my crazy cat comes in. He keeps me occupied, often by washing my face and hands, kitty style. That's fine, but sometimes he also heads to the bathroom and flushes my toilet, which isn't so fine when you're lying there needing to pee . . .

Once my attendant arrives, I'm hoisted out of bed, and prepared for a shower. Now, I am not a morning person, so it must be hilarious to see me, a bed-headed spastic quadriplegic, still drooling with sleep, dragged all snoring and crusty-eyed to the shower. It is only after the showering process ends that I begin to feel human. After showering, it's on to the dressing routine, which is a unique experience each time. It seems my attendants still have difficulty understanding the concept of *left leg* and *right leg* when I'm being dressed. I hope they will understand soon, because sometimes I feel like a chicken being trussed for dinner. On occasion my friends tease me because they can tell who got me up on any given morning, since each attendant has her distinctive style. I guess they never played with dolls when they were kids. Anyhow, after I'm dressed I eat my breakfast (I hate breakfast, but I eat it anyway, because of my active lifestyle) and brush my teeth, then rush out the door, like just about everybody else.

My life is busy by necessity and design; besides my job as Family and

Individual Support Worker for the Cerebral Palsy Association of BC (CPABC) I am occupied with volunteer activities, a social life, managing my attendant care and CP, which means regular trips to the gym, swimming, and various other therapies, and oh yes, I'm also a university student . . . seems there needs to be two or more of me these days; or I need to be *Super Quad*. *Super Quad* is very popular now; until a totally inclusive society is as much a reality as it can be, there's always a new issue up for debate or advocacy.

COMING AND GOING

I'm lucky; I can do a lot of my work from home, but even so I'm at the office several times a month for meetings, administrative catch-up and so on. *Off to work* means relying on accessible public transportation, and that means having other people prioritize my request for a ride. It can also mean a substantial wait, so I make sure I've got a book, or some paperwork along. I also need to think ahead to the actual bus stop: is there a shelter where I'll be waiting, or will I be at the mercy of Vancouver's mercurial elements? I'm not very waterproof .

On gym days, those that don't recognize me try not to stare, but since we're surrounded by mirrors, their efforts are both pitiful and funny. I usually ignore them and go about my own business, but once in a while I get to show up an upright, my term for those of you who are able-bodied. I like to throw a monkey wrench into those preconceived notions of what a person with a disability can accomplish. It's fun, and I try not to gloat.

I've had 37 years to develop the sense of humour that helps me deal with the attitudinal and systemic barriers that still prevail. As a kid, I hadn't yet accessed this important tool, and so dealing with inclusion—and exclusion—was a hit and miss proposition. Disability is a fact of my life; inclusion needs to be a fact of life, too, but not one that demands we all become Super Quad, or get pushed relentlessly into the *normal* end of the ability spectrum. My disability is part of who I am but it doesn't define my personhood. My hobbies, interests, and relationships supercede the limits of my physical

disability. The support of friends, family, and professional relationships has allowed me to focus on my strengths while acknowledging the presence of weakness.

CHAOS WITHIN ROUTINE

Just when everything is running smoothly, along comes an early morning conference, course, or speaking engagement. This throws everything in disarray and necessitates a quick change of plans for everyone. Not only am I up at the crack of dawn, but my attendants scramble to get me ready in record time, and some of them aren't morning people, either. I end up rushing out the door with the attendant in my dust and Rocket looking at me as puppyishly as is possible for such an eerily yellow-eyed creature.

Not everything is a bed of roses; I have frustrations, and good and bad days like everyone else. I have to live within the confines of the systems that support me and assist in carrying out my daily activities, ensuring my needs are met. Despite this I am ambitious and determined; I set goals and achieve them.

One of those goals is to see inclusion become a societal norm; this is one of the points of my job and my continuing education. I remember when inclusion was a new idea, so I know how important it is to assess each child individually, taking into account their varying degrees of ability. Not everyone will achieve the same level of functioning; the point of inclusion should not be to turn out grand classes of Super Quads but to ensure that everyone gets the same chance to reach their full potential in life, and enjoy it like everyone else. Inclusion has allowed me to be an active member of my community; but inclusion cannot change everything. I still have a disability, and no matter how successfully inclusion deals with barriers, there will always be people who only notice my differences. But after I've been tucked into bed at the end of the day, what matters most is whether or not I'm happy with who I am, and what I've achieved, disability and all. ~

Inclusion—What is it All About?

The purpose of special Education is to enable the equitable participation of students with special needs in the educational system in British Columbia.

—BC MINISTRY OF EDUCATION: *Special Education website* 2006

Inclusive education is mandatory in British Columbia. It can look different between school districts, schools, and classrooms. *Inclusion means all students learning together in the same room, with different educational goals and abilities, but all contributing to a diverse learning environment.* The benefits of inclusion grossly outweigh the disadvantages. All students develop better in academics and in social interactions as a result of this setting.

Creating a fully inclusive setting means more than having all students in the same room or school, but rather allowing everyone to participate in group activities and maximize their strengths and abilities, while developing methods to overcome challenges in a safe and caring environment. Integration was the bridge between segregation and inclusion. *Segregation* was *where children with disabilities were educated in separate classrooms and schools,* and integration was the beginning of having all students together. However, in the latter, the children with special needs often remained at the back of the class, doing completely different activities from other students, and had little social interactions with typical children. Inclusion allows children with unique capabilities to do similar activities as the typical children with some modifications and adaptations. When we really think about it, all children have different learning styles, and each student will experience greater success by one teaching method from another, and so

when we consider this, inclusion is just an extension of what we know is true of all students.

The benefits of inclusion for the child with special needs are numerous. Good modeling of appropriate behavior is invaluable. Children who receive their education in a segregated classroom typically replicate undesirable behaviors which are around them; behaviors which are normally not seen in their form of disability. For example, a child with a physical disability may display poor social skills because they have not observed good social interactions in their environment, but in an inclusive setting they could thrive in this area. As well, segregated classrooms do not motivate children to succeed because there is no pass or fail. Norman Kunc refers to the classroom with poorly modeled behavior and the lack of motivation as 'Retarded Immersion.' (Kunc, page 2). Following formal education, children with disabilities, who have been fortunate enough to be taught in an a fully inclusive setting, generally demonstrate increased community involvement, better social connections, and greater income potential, according to BCACL (British Columbia Association for Community Living, page 7). Children who have been taught in a segregated classroom often can't use the skills outside of the classroom, because some individuals have difficulty generalizing the information to life scenarios or knowing how to relate to peers who are not disabled.

The benefits of inclusion are not limited to the child with special needs, but are advantageous to the typical student. In the past, parents were concerned about the education of their fully able-bodied child with children with disabilities. It was feared that typical children would receive less attention, and pick up undesirable behaviors. However, time has dissolved some of these early apprehensions. Inclusion has resulted in children who are more accepting of differences, have increased interpersonal skills, greater maturity levels, and demonstrate improved values and attitudes (BCACL, page 8). Typical children also learn responsibility when in a fully inclusive setting and have the opportunity to be mentors. There are *two* levels of learning: 1) understanding to pass a test, or foundational level, and 2) having

a deep knowledge in order to teach someone else. Inclusion can improve children's understanding of concepts taught in class. Diverse interactions benefit the entire class.

Inclusion can be both obvious and inconspicuous. Some disabilities, such as dyslexia, learning delays, or language barriers may be difficult to detect at a quick glance around the room, while other disabilities that have physical differences such as unique facial features, wheelchair use, or movements that seem awkward, can be identified immediately. In either case, additional help to make inclusion possible may exist, like the presence of a resource teacher, or SEA, for occasional pull-out programs or, in class support, as well as adapted materials to suit individual needs. Although additional support is required to facilitate inclusion, the inclusive classroom should look like any classroom. All children should be participating in both academic subjects like math, language arts, science, and social studies, but also in the electives like music, physical education, and library. The child with special needs requires a broad teaching of subject matter as do typical children. Inclusive education does not mean excluding students with special needs from academics because it may be too difficult for them, so they shouldn't just play all day, nor should educators be so focused to teach the ABC's and 123's , that the child misses out on some of the fun electives that the other students are enjoying. A healthy balance must be maintained. Fieldtrip inclusion is necessary, for not only does a child with special needs receive a sense of belonging, but they also learn appropriate social behavior and have a chance to develop relationships with peers.

Whether in an elementary school, or in a secondary school, the modified or adaptive materials should be age-appropriate so the child with special needs does not stand out. An elementary student can learn shapes by playing with blocks, and colouring and cutting shapes. For high school, a more appropriate way to teach shapes would be to use a driver's manual: there are a variety of shapes in the manual, such as octagons, triangles, pentagons, squares, rectangles, and diamonds. The previous materials can be used as

modifications for a geometry unit. A method of modifying a spelling exercise is to have children practice the first letter while the others are spelling entire words on chalk boards as these words are being dictated by the teacher. For a secondary student with special needs, they can practice spelling and other English-related topics on the computer, for this will again allow the child with special needs to use the same tools as their peers to obtain their personal academic goals. These are only a few suggestions to facilitate inclusion from an unlimited list of modifications and adaptations.

In order for a student to receive the supports they need to accomplish their academic and social goals in school there needs to be a label attached to that student; however, when instructing the student we must see beyond the label and focus on the unique gifts and talents they have to offer to peers and educators. We need to have high, but not unreasonable, expectations for all pupils in order for them to be motivated. Yes, inclusive education has come a long way from segregated schools, and even integrated classrooms, but it still is a 'work in progress.' ~

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The Inclusive School

Inclusion gives a chance to a child, to be part of *an inclusive school setting* that *provides a positive feeling of competence that others believe that the child can succeed*.

An inclusive educational setting provides children opportunities to participate in activities that allow them to understand what is the norm. The child can acquire the physical and social competencies needed to function in their school, home and the community.

A school's policies and values lead to particular expectations and behaviors on the part of staff members and all the children. A school that supports inclusion has high expectations for its staff members and all the children, provides opportunities for their participation in the classroom and broader school setting. Feelings of acceptance are promoted by a welcoming inclusive school atmosphere; an inclusive school culture that accepts different kinds of behaviors in the classroom doesn't make assumptions about the children's ability.

A child greatly benefits from an inclusive school setting. It provides preparation for adult living. Children who may experience limited abilities can practice skills in the actual community settings where they are needed and the child can develop a sense of belonging. Inclusion provides greater exposure and improved learning through peers. When children with special needs are placed in regular classes, they have the chance to develop socially as well as academically through peer models and exposure to a broader variety of experiences.

When all children interact in class, they are provided with opportunities to break down barriers and help one another to understand each other better, thus helping to create a society that accepts and values all people as

contributing members of society. Having an inclusive setting provides a chance for friendship development among children who vary in learning abilities. Children can become friends with one another in a classroom. Some of the friends that they make in school today could be their co-workers and fellow community members as the children reach adulthood.

Inclusive education is characterized by focusing on the child's strengths, rather than the child's weakness. By focusing on developing the child's strengths, educators are encouraged to look closely at areas where the child is functioning most like his/her peers, and these strengths can be used to facilitate positive interactions with classmates along with learning and intellectual development.

Many strategies can be used to promote social inclusion among all children such as the use of seating arrangements that expose children to role models and setting up buddy systems to support the child with special needs.

Inclusion benefits all children in a learning institution. All children have the right to be part of a community, to feel accepted and experience that sense of belonging that is universal amongst all children. ~

Is Your School Accessible?

Accessibility—having no barriers which hinder the attendance or participation of any person.

- Does your school have ramps, elevators, or stairwell lifts for all level changes, both inside and outside the building?
- Does it have doorways wide enough for a wheelchair to go through?
- Can doors be opened by someone in a wheelchair, or with restricted motion?
- Do the doors have lever handles rather than knobs?
- Are the doors automatic or sliding?
- Is there room in hallways for a person using a wheelchair to turn into a doorway, or to make a 180° turn in direction?
- Is there room in the washroom to turn the wheelchair or to transfer from the chair to the toilet?
- Are all towel, paper cup, sanitary supplies, soap dispensers, water fountains, mirrors and sinks, low enough for a person in a wheelchair to use them independently?
- Can the door be opened, for an easy exit once inside the washroom, by someone in a wheelchair, or with restricted motion?
- Are telephones, emergency buttons and alarm pulls positioned so that they can be used from a wheelchair?
- Can a person with mobility restrictions get into the auditorium and onto the stage?
- Have plans been made, and practiced from all levels of the building, for emergency evacuation of a person in a wheelchair?
- Are there safe curb cuts from cross streets to the school property?

We Have a Dream

We have a dream that every child will be born into a world that values that child's individuality, and his or her right to equal opportunities, regardless of their disability.

We have a dream that all our children, with or without disabilities, will be able to live, play, learn and work together, each one helping the other.

We have a dream that inclusion of children with disabilities into regular classrooms will be achieved as appropriate for each child.

We have a dream that this inclusion will extend to the whole community as young adults, with self-determination and appropriate supports, embark to live and work among us rather than apart from us.

We have a dream that young people will learn that *we are more alike than we are different,* and that discrimination or abuse will not be tolerated.

We have a dream that every parent will be able to find the necessary information and support to provide for their child's special needs.

We have a dream that parents will be acknowledged as the *experts* on their child, and that parents and professionals will meld their experience, their expertise and their love for the benefit of the child.

We have a dream that more families will gain access to assistive technology to enable their child to learn and to communicate more effectively.

We have a dream that all people will become standard bearers for the right to equal access, and will make public services and accommodations, transportation, employment and communication truly available to all.

We have such dreams for our children. We know that as these amazing dreams evolve and our children grow, we will not cease to nourish them and to advocate for them. We will not cease to explore every way possible—and impossible—for our children to share in and contribute to society. Together we will use our minds, hearts and our abilities to create a world in which we can all live and achieve what was once . . . just a dream.

—From *The Pacesetter*

Being at Ease with Children Who Have Disabilities

What to Focus On?

For years people with disabilities have been segregated from the rest of society as if they were truly different from other people. Because of changes to the BC Education Act, children with disabilities are now to be educated in the *least restrictive environment* wherever possible, in the regular classroom. It is sad that attitudes cannot be legislated too, but fears and anxieties toward those who are different cannot be decreed illegal. It is hoped that the present generation, growing up in situations where people with disabilities are a natural part of school and community life, will put to rest forever the notion that people with disabilities are 'different.'

For those people who have never known a person with disabilities, and are suddenly faced with the new experience of having a child who needs extra supports in their classroom, scout troop, or community activity, it helps to focus on the fact that a child with a disability is a child first. A child with a disability has many attributes, such as brown hair, brown eyes, a turned up nose, an inability to hear, and so forth. By thinking of a child's disability as just one of his many characteristics, the anxiety often anticipated when a youngster with a disability is scheduled to join a program can be greatly reduced.

What Special Treatment should be given?

Children with disabilities need to be treated, as much as possible, like any

other child. It is unfair to the child when he or she is not allowed to compete. The world at large is mainly inhabited by people with the ability to see, hear, speak, and move about freely. Children with disabilities need to practice meeting the standards of the 'normal world' while they are growing up so they can gain confidence and independence.

How Can One Help but Feel Sorry for Children with Disabilities?

If you perceive the child who has a disability as someone to be pitied, someone from whom little should be expected or demanded, probably little will come. If, on the other hand, you expect the child to succeed and grow, to learn to act independently, then chances are good that the child will become a successful, growing, independent student.

How Should Frustration or Temper Tantrums be Handled?

Such problems should be handled the same way they would be handled if the child did not have a disability. It is easy to assume that people who live with a disability exist in a continuous state of frustration. This is not true. Of course children with disabilities may feel frustrated at times. These frustrations should be handled with good sense, remembering that a certain amount of frustration is healthy and promotes growth, but that too much frustration can be defeating.

How Should You Respond to Everyday Accomplishments?

It is a joy to see a child with a disability able to do the same things that other children do, such as read, play on the jungle gym, or go through the lunch line. It is important, however, to distinguish between accomplishments that are attained with about the same degree of effort that is required from most children, and those accomplishments that really represent a challenge to

the child with a disability. If people react to ordinary accomplishments that were not particularly difficult to attain as if they were extraordinary, children can develop unrealistic views of themselves—either an inflated view of their capabilities and accomplishments, based on the continual amazement elicited from others, or a deflated view, based on the obviously limited expectations others hold for children with disabilities. On the other hand, encouragement and reinforcement should be expressed when youngsters accomplish tasks made difficult by their specific disabilities, for example, dressing for a child with cerebral palsy.

How Much Help should be given?

One of the benefits of mainstreaming is that children can help their classmates who have disabilities. But too much help can become a hindrance if it robs the child of opportunities to learn and practice independence. Generally if a child cannot handle some procedure or material, she or he should be taught how to do it if at all possible.

Do Children with Communication Problems Also Have Problems in Thinking?

One disability that people have trouble coping with involves speech and language. Whether the communication impairment results from a physical disability such as cerebral palsy or a speech difficulty such as stuttering, the listener tends to anticipate what the disabled person is trying to say and does not allow the person the time she or he needs to communicate. It is easy to mistakenly perceive people who have severe communication disabilities as also having impaired intelligence because of their simple, poorly articulated speech. This should be avoided. Individuals who have problems expressing themselves, unless they are also hearing impaired, generally have no problem understanding normal, complex language.

Isn't There Anything Special that needs to be done?

There are special considerations that can be helpful to children with specific disabilities. For example, keep in mind that children who have visual impairments depend on what they hear and touch to bring them information about their surroundings. Provide opportunities for children who have visual impairments to handle things that children with normal vision can simply look at. It is also helpful to describe new people, things, and events as they come into the child's environment. Allow time for the child to ask questions about what is going on.

Children who are intellectually disabled can get along better when directions are short and clearly stated. Break down tasks into a series of steps that can be completed in sequence. Maintain a routine, teach new procedures, and give time for practice.

Youngsters with orthopedic impairments should be asked whether they need help and, if so, what kind. Do not assume the child needs more help than he asks for. ~

—Adapted from *ERIC Digest #366*, and brought forward from first publication of *Putting the Puzzle Together*

RESOURCES:

Attitudes and Attitude Change in Special Education: Theory and Practice, REGINALD L. JONES, Editor (1984)

Reflections on Growing Up Disabled, REGINALD L. JONES, Editor (1983)

Supporting Visually Impaired Students in the Mainstream, by GLENDA J. MARTIN and MOLLIE HOBEN (1977)

Inclusion of Students with Severe Disabilities

WHO ARE THESE STUDENTS?

Students with severe disabilities are those "having physical, mental, or emotional problems to a degree requiring educational, social, psychological, and/or medical services beyond those traditionally offered by regular and special education" (Kelly & Vergason, 1985, p. 156). They typically lack skills such as ambulation; the ability to communicate their needs easily; and/or self-care skills, particularly dressing, toileting, and independent eating.

What are some benefits of inclusion for these students into the regular classroom?

Students with severe disabilities can benefit from well-planned and organized integration experiences. In integrated school environments, regular class students are provided unique opportunities to learn firsthand about human differences and similarities and how to approach and interact with members of society who have severe disabilities. Researchers have found that, generally speaking, non-disabled students who have had opportunities to interact with students with severe disabilities hold more positive and accepting attitudes toward them than do students who have not had such opportunities (e.g., Voeltz, 1982). Such interactions can also reduce non-disabled students' fear of students with severe disabilities and promote understanding (McHale & Simeonsson, 1980).

What needs to be done to facilitate inclusion?

Teachers who have been involved in integrating students with severe

disabilities have found that careful planning is required to take full advantage of the available interaction opportunities. In other words, positive interactions between students with severe disabilities and others in a regular school environment will rarely happen spontaneously at first; they must be planned for and encouraged in a systematic fashion until the students get to know and feel comfortable with one another.

How can problems associated with access and scheduling be overcome?

Special and regular education staff should discuss issues such as school transportation (Will the students with severe disabilities be able to ride on the same buses as their non-disabled peers?); and position of students with disabilities in the lunchroom (Will they sit with lunchroom partners who have disabilities or at tables with non-disabled students?). Many modifications in typical school routines (early lunchroom arrival or departure, entering school through a separate door, sitting at a separate lunch table) made initially to minimize difficulties for student with severe disabilities, either are unnecessary or soon become unnecessary. Modifications of building usage, scheduling, or program access should be minimized or avoided if at all possible.

Where can extra help best be used?

Areas in which additional support might be needed could include getting on and off the bus; using correct entrances and exits; locating classrooms, bathrooms, offices, and other school facilities; using lockers and locks; following lunchroom procedures; and using recess time in appropriate ways. It is important to plan to gradually fade out the additional support as students begin to acquire necessary skills and learn new school routines.
Students with disabilities should not always be the recipients of assistance from others. All students, including those with disabilities, should be given opportunities to be providers as well as recipients of assistance. (Stainback & Stainback, 1988)

How can extracurricular activities strengthen the integration of students with severe disabilities?

Most schools have co-curricular activities including clubs, sports, newspaper, student council, and social events such as dances. Many students with severe disabilities can acquire the skills necessary to participate, at least partially, in some of these activities. For example, students with severe disabilities could participate in the production of the school newspaper by collating, stapling, and delivering the newspapers to each classroom. They could also participate in student council meetings. Participation in any of these activities can provide both students with severe disabilities and nondisabled students opportunities to work together in a positive manner. ~

—Adapted from ERIC *Digest #E468* and brought forward from first publication of *Putting the Puzzle Together*

REFERENCES

GARTNER, A., & LIPSKY, D. (1990). *Students as instructional Agents*. In W. STAINBACK & S. STAINBACK (Eds.), *Support networking for inclusive schools* (pp. 81–93). Baltimore: Paul H. Brookes.

Children Will Grow Up

You and I did.
They will not wait,
As we did not wait, to be
Helped or Healed.

If a child is given the kind of care
And the quality of care needed when young
Then we can be proud,
For the joy and hope of life
Will be theirs.

No matter the severity of the disability,
The extent of a limitation,
The prognosis of a disease,
To allow needs to go unmet
Is wasteful. ~

Author Unknown.

Section 2

Blueprint for the Classroom

Individual Education Plan (IEP)

My entire life changed the moment I realized that I had the right to be disabled; that I was under no obligation to anyone to minimize my disability and that my disability was simply one part of the diversity of people.

—NORMAN KUNZ (2005)

WHAT IS AN INDIVIDUAL EDUCATION PLAN?

An Individual Education Plan (IEP) is a written working document that is designed to identify any changes or additions that will be made to the regular educational program of a student with special needs. This document describes any program adaptations, modifications and/or services that are necessary in meeting a student's specific needs.

In the Order of the Minster of Education (1995), a student with special needs has one or more of the following:

- A disability of an intellectual, physical, sensory, emotional or behavioral nature
- A learning disability, or
- Exceptional gifts or talents

When a student is assessed and identified as having special needs, an IEP is developed that will meet that student's individual needs and serve as a collaborative tool for planning, implementing and communicating the student's specific learning goals and objectives; thus, the purpose of the IEP

is to enable students with exceptionalities to develop their own individual abilities, strengths and potential.

According to the B.C. Ministry of Education (2005), the IEP is:

- A concise and usable document which summarizes the plan for the student's education program
- A tool to assist teachers in monitoring and communicating student growth
- A plan developed, implemented, and monitored by school staff in consultation with others involved with the student
- A flexible, working document with meaning for all contributors
- An ongoing record to ensure continuity in programming

The IEP is not:

- Written in stone
- A daily plan, or a description of everything that will be taught to one student
- A means to monitor the effectiveness of teachers
- A report card (however, the report card should comment on progress towards IEP goals)

WHEN IS AN IEP NECESSARY?

An IEP is necessary when a student's program is either adapted or modified.

On an adapted program, the learning outcomes for the student remain the same as those prescribed in the regular curriculum—the goals remain the same, but the means to achieve those goals is altered. For example, adaptations can provide students with alternate formats (Braille, books on tape), instructional strategies (interpreters, scribes, visual cues) and/or

assessment procedures (oral exams, additional time). The specific adaptive materials, instructional strategies and/or assessment methods are identified in the IEP. Students on adapted programs can achieve grade-level learning expectations and be granted full course credit for their efforts; therefore, they have the opportunity to achieve prescribed learning outcomes that meet the provincial graduating requirements for a Dogwood Certificate.

On a modified program, the learning outcomes are significantly different than those prescribed in the regular curriculum. In this instance, the IEP will include modified curriculum expectations that state the individual or personalized goals and objectives of the student with special needs. Teacher reports for these students will include details of what the student is able to do, areas for further attention or development and ways of supporting the student in relation to their individual learning outcomes. At the completion of the student's final year of school, students on modified programs are eligible to receive a British Columbia School Completion Certificate.

An IEP is only necessary when students require adapted or modified programs. Areas of study in which the student is following the curriculum, without the need for adaptations or modifications, will not be included in the IEP. In addition, if the adaptations are minor, and can be accommodated within the regular classroom, without the need for additional resource or learning assistance support, an IEP is not required.

WHAT INFORMATION SHOULD BE INCLUDED?

An IEP can vary in length and complexity depending on the needs of the individual student. According to the Ministry of Education (2005), IEP's for students with special needs must include one or more of the following:

Individualized goals for the student

- A list of support service required by the student, may include a description of the time and setting for the special program, names and roles of individuals who will be involved and the strategies and/or teaching methods to be used

- A list of the adaptations and strategies planned to help the student meet the outcomes established for him/her
- Information from teachers, parents or related service providers concerning the student's needs
- A description of the student's current learning and information on strengths and needs from assessment results
- Appropriate intellectual, social, emotional and career/work goals for the student
- Target dates for progress towards the goals with a review date to see progress made by the student
- Short term objectives which will provide direction and indicators of progress
- A description of how the student's progress will be measured and evaluated
- Plans for transitions to the next setting
- Relevant information about the student's medical, social and education background
- Information about the student's current learning strengths and needs
- Degree of participation in the regular classroom
- Program area where a student needs program adaptation and/or modification
- The date for the annual review (if necessary, more frequent)

WHO IS INVOLVED AND WHAT IS THE PROCESS OF PUTTING AN IEP IN PLACE?

Once a decision has been made that a student requires an IEP, a team should be formed to plan for the student's educational needs.

The IEP team:

The school based team should be chosen based on their ability to provide information or support for the student's program. In cases where the student has needs in a specific area, the team may only consist of the principal,

teacher, the parent and student (if appropriate). When the student has many needs the team is extended to assist the student in achieving educational goals.

According to the Ministry of Education (2005), participants of the school based team usually include:

- The classroom teacher
- The school administrator
- Parent or legal guardians and the student (if appropriate)
- Other school based and District support staff: counselor, psychologist, speech/language pathologist, physiotherapist/occupational therapist, teacher assistant, learning assistant and resource teachers

Establishing an IEP team enables the members to:

- Develop a common understanding of the student's strengths, interests and needs
- Share information and observations of the student's behavior and learning in a variety of settings
- Understand programming priorities for the student and reinforce them across the curriculum
- Plan in an effective and efficient manner

Parents should be encouraged to be involved in decisions regarding educational services for their children. They provide a unique perspective about the student's personality, development and learning. Open communication and cooperation between home and school increase the opportunities for students with special needs to experience success. —(Ministry of Education, 2005)

IMPLEMENTING AND REVIEWING THE IEP (MINISTRY OF EDUCATION, 2005)

Because the IEP is a working document, it must be linked to the ongoing instructional planning to be effective. The student should first be seen as a

student in the class, and not be defined completely by those special needs. Implementation of the IEP is putting into practice the plans, strategies and supports agreed upon by the team members. This usually includes one or more of the following:

- Modifications to the curriculum
- Adaptations to instruction and/or assessment methods
- Use of adaptive/assistive technologies
- Changes to make the learning environment more accessible
- Provision of support services and of specialized training (mobility and orientation: sign language instruction etc.)

Reviewing the IEP:

Throughout the development of the IEP, the support team involved should decide when and how to monitor the student's progress and the relevance of the plan. The best way of handling these reviews may be to include them with the regular reporting procedures. Doing this will avoid having to hold separate meetings and provides the information needed for the report card.

Preparing for the IEP review meetings is similar to the initial IEP meeting. The person coordinating the IEP should organize the meeting and all team members should share information on the strategies used and the assessment results since the last meeting. During this review meeting, the team may decide to continue using the current plan or to change the goals or adaptations or seek additional help from other district or community sources.

Questions that may help to guide the review process:

- Is the IEP an accurate reflection of the student's current programming needs?
- How effective are the strategies and resources selected to support student learning?
- How much progress has the student made toward achieving the goals and objectives set at IEP meetings?
- Should new goals be selected and new objectives created to more

accurately reflect the student's changing strengths, needs and interests? (Ministry of Education, 2005)

What does an IEP look like?

IEP's are different depending on the individual school and school district. There are many variations of IEP formats. No specific version is considered more or less correct, so long as the required information is included, and the participants find the document useful.

> *Transition is a process which should be planned well in advance and incorporated into the IEP.*
> *—BC MINISTRY OF EDUCATION: Special Education, IEP website 2006*

REFERENCES

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www.bced.gov.bc.ca
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BRITISH COLUMBIA TEACHER'S FEDERATION (retrieved May 9, 2005) www.bctf.ca
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Permission to include IEP planning sheets in this publication granted by K. CHAMPION, (developer) Richmond School District.

INDIVIDUAL EDUCATION PLAN

(Sample Form 1)

Student Name _____ Birth Date: _____ Student Number: _____
School: _____ Grade Class: _____

Parents/Guardians Address: _____ Home Phone: _____
_____ Work Phone: _____

ASSESSMENT/PLANNING INFORMATION

Current Level of Performance

_____

_____

_____

Strengths:	Needs:

Goals

Goal:	Date Established:	Team Members Responsible:

Short Term Objective	Strategies and Resources	Assessment Procedures

Results: _____

Team Members:

Name, position and signature acknowledging agreement of goals and objectives

_____ school administrator _____ classroom teacher
_____ parent _____ classroom teacher
_____ parent _____ classroom teacher

Review date(s): _____

Comments:

_____

_____

_____

_____

Recommendations:

_____

_____

_____

_____

SD 38 (Richmond)

Matrix IEP

NAME: _____ GRADE: ____ SCHOOL: _____ DATE: _____

	Student will	Supports	Student will	Supports	Student will	Supports	Student will	Supports

 SD 38 (Richmond)	**What do we need to do to help the student be successful?** *List the types of support the student will need to move toward the goals*	**How is the student progressing?** *Comment on how well the student has done.*
	Strategies/Materials	Progress Notes
Initial Period *Dates (Term 1)*		
Review Period 1 *Dates (Term 2)*		
Review Period 2 *Dates (Term 3)*		

SD 38 (Richmond)

IEP/ICP Planning Sheet for Students

STUDENT'S NAME _____ DATE _____

Dear _____

We are interested in developing the best possible program for you and would like your assistance in preparing for the IEP meeting.

What do you feel are your strengths?

_____

_____

In what areas do you need support?

_____

_____

How do you learn best?

_____

_____

What are your interests/talents/hobbies?

_____

_____

What behaviours are stopping you from being successful in school and in the community?

_____

_____

What are your main hopes this year?

_____

_____

Do you have any particular concerns about your school program this year? If so, please describe.

_____

_____

IEP/ICP Planning Team will include:

_____ _____ _____

_____ _____ _____

_____ _____ _____

Thank you for taking the time to respond to these questions.
The IEP meeting is scheduled for:

Date _____

Sincerely,

_____
IEP Team Coordinator

IEP/ICP Planning Sheet for Students, Rev. Dec/01

SD 38 (Richmond)

IEP/ICP Planning Sheet for Team Members

STUDENT'S NAME _____ DATE _____

IEP/ICP Planning Team

_____ _____ _____

_____ _____ _____

_____ _____ _____

To develop the best possible program, and to use our planning time efficiently, I am requesting your assistance in advance of the meeting by responding to the questions below:

What do you feel are the strengths of your student?

_____

_____

In what areas does your student need support?

_____

_____

How does your student learn best?

_____

_____

What are your student's interests/talents/hobbies?

_____

_____

Does your student have any fears or behaviours which are of concern to you? If so, please describe.

_____

_____

What are your main hopes for your student this year?

_____

_____

Do you have any particular concerns about your student or his/her program this year? If so, please describe:

_____

_____

Thank you for taking the time to respond to these questions.
The IEP meeting is scheduled for:

Date _____

Sincerely,

_____
IEP Team Coordinator

IEP/ICP Planning Sheet for Students, Rev. Dec/01

Adaptations and Modifications

In any average classroom, there will be some students who will experience difficulty with the course material as it is presented to the class as a whole. These students generally fall into two categories: first there are the students with processing disorders or physical disabilities which impact their ability to comprehend the course material, and second there are students with intellectual difficulties who do not have the ability to complete the course material.

The first group of students is able to meet the prescribed learning outcomes with format changes or *adaptations* to the course material. With such additional support, they can successfully meet the course requirements and will therefore receive credit like everyone else. The students in the second group are not capable of meeting the prescribed learning outcomes because they cannot understand the concepts, and need to have their course material *changed* or *modified* to create unique learning outcomes designed specifically for their individual needs and abilities. They can be included in the course activities, and can learn, but will not receive a letter grade or credit for the course.

Students who are on an *Adapted Program* follow the same curriculum as the other students. They are assessed using the learning outcomes for the course and receive credit for the course if the outcomes are met. Students in grades 4–12 receive letter grades. Adaptations should be noted in an *Individualized Education Plan* (IEP). Adapted programs give students the potential to receive a Dogwood Graduation Diploma. Adaptations may also be used when a student writes provincial exams once an application submitted by the school principal is approved. The following options and examples

for adapting curriculum are taken from *Students with Intellectual Disabilities A Resource Guide for Teachers.*

Adapting the classroom environment:

- when seating a student in the classroom take into account lighting, noise, smells and location
- help the student become organized with colour coded duotangs, a timetable in their binder and a day timer to write assignments in

Adapting the presentation:

- highlight key points in the textbook for the student to read
- repeat and simplify instructions
- ask the student to repeat directions to strengthen their understanding
- prepare a summary with blanks for the student to fill in while listening
- complete the first example with the student
- change tone of voice to cue student and sustain attention
- use both auditory and visual presentation, use multi-sensory examples
- use high contrast material for the student with visual impairment

Adapting materials:

- enlarge or shrink materials, put less information on a page
- use a calculator, use manipulatives
- dictate to a scribe
- built up pencils or pencil grips
- word processing on a computer, computerized voice system, use of Braille
- highlight or colour code directions, key words, topic sentences etc.
- use different types of paper e.g. graph, mid-line paper, raised line paper

Adapting assistance:

- peers can assist by: modeling, reading, scribing, answering questions, clarifying instructions or helping to organize
- classroom assistants can work with the whole class as well as the student with special needs and carry out many aspects of the student's individual plan, be an interpreter or explain instructions
- learning assistance, resource or consultant teaches can support instruction for the student in the classroom, provide problem solving assistance to the teacher and team-teach to allow the classroom teacher more time to deal individually with the student

Adapting ways of representing knowledge:

There are many ways that a student could show that they have met the learning outcome. Here are a few examples: song, report, poem, puzzle, visual art form, diary, commentary, poster, speech, charades, invention, skit, radio commercial, pantomime, model and a puppet show.

Adapting evaluation:

- keep evaluation strategies simple: evaluate on IEP progress, set small goals, keep work samples, do spot checks, enlist the support of the SEA
- vary strategies: set up self evaluation, observe demonstrated knowledge, use video, use individualized criteria, set up peer evaluation, use an objective observer
- tests: use a scribe, conduct an oral test, read test questions to the student, permit the use of calculators, allow extra time to complete the test

When *adaptations* are not sufficient to meet the needs of a student it will be necessary to *modify* the learning outcomes. A modified program focuses on learning outcomes that are substantially different from the prescribed

learning outcomes for the grade or course. These learning outcomes are specifically selected to meet the needs of the student and are outlined in their IEP. Written comments are used to report the student's level of success in meeting the learning outcomes. There are no letter grades given for a modified program. A student may receive a School Leaving Certificate, which represents their achievement of the IEP learning outcomes. The individual learning outcomes should be developed by a school-based team, in consultation with parents or guardians, and are part of the creation of the student's IEP.

It is important to remember that a student could be on an adapted program for one course and not others, also a student could be on a modified program for one course and not others. To further clarify the differences between adapted and modified programs, the following list shows some examples of each:

- James can not do math problems beyond simple arithmetic, his grade 8 math work is modified to reinforce his skills working with money, balancing a check book, etc. James does not receive credit for math 8; he receives a comment explaining his modification as part of his IEP.
- Joey has a math processing disorder and can not multiply in his head but he understands mathematical concepts. He is allowed to use a calculator during all his high school math work. This is an adaptation and Joey receives full credit for his work.
- Judy's reading level is at about a grade 4 level. She can read the words in the socials 8 text but she can not retain the information or understand the key concepts. She does all the work as the other students with the help of a SEA but is not tested as the other students are. Judy's course is modified; she does not receive credit.

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Adapting Curriculum, *www.bced.gov.bc.ca/specialed/sid/21.htm*
Modifying Curriculum, *www.bced.gov.bc.ca/specialed/sid/27.htm*

Types of Classroom Learning

COMPETITIVE

Competitive learning is the old school of generations past; where student was pitted against student. There was always one winner, and a class full of losers. Competition is acceptable where all have equal potential; where any one could be 'the winner' if he/she just tried hard enough. Competition is unacceptable where the base is not level; where one child will always 'lose' because of factors not connected with either the desire to learn or the amount of effort expended.

INDIVIDUALISTIC

Individualistic learning is what is developing with the increase in home-school situations, where the student learns at his/her own pace, without reference to other students. This can also occur within the regular classroom, when students are evaluated on their own progress and increasing abilities, not on their performance with respect to others.

COOPERATIVE

Cooperative learning happens when students work as teams, each sharing his/her own abilities and knowledge with other members of the team. Evaluation is done on a team basis, so it becomes important to each member that everyone participates and everyone learns. ~

Guidelines for Teaching Students who have Mild Disabilities

- Explain skills and concepts in a concrete, realistic manner
- Avoid digressions
- Organize material into meaningful segments
- Use reinforcement and incentives
- Use plenty of drill and practice
- Teach children rehearsal strategies
- Do not teach skills in isolation—relate teaching to other subject areas, and especially to everyday matters.
- Avoid calling on students unless you are sure that they want to contribute
- Instruct small groups for only short periods; twenty minutes is probably enough, and never more than thirty
- Insist on accuracy and ensure mastery at one level before moving to the next
- Before presenting any materials, assess the level of readability
- Preface all remarks with a title, or the main idea of the lesson
- Indicate the important points during a lesson by saying, for example, 'listen carefully', or 'this is important', and then change the volume and tone of your voice.
- Vary presentation, so that both written and visual components are included
- Use diagrams and visual materials frequently so that the students may grasp ideas without depending solely on language
- Never assume that pupils have heard and comprehended until you have asked them to repeat the information verbally

- Give advance notice of each required task by statements such as, 'when I blow the whistle, you go to the white line.'
- Immediately after teaching an important concept, check the student's power of recall
- Make sure that all paperwork handed out is legible
- Allow short answers to questions
- Allow slow writers enough time to finish tests
- Post all crucial information on the board in note form
- Provide self-tests and checklists so that students can monitor their own progress
- Teach students to scan exam papers and to underline key words
- Modify grades to reflect intra-individual differences
- Provide for over learning ~

—Taken from *Closing the Gaps* by Margaret Winzer

Teaching Students with Speech and Language Problems

- Establish a relaxed atmosphere in the classroom to allay student's fears
- Be a good speech model
- Allow students many opportunities to speak
- Enrich student's language and speech by consistently naming objects and events, and reinforcing usage
- Promote good listening skills
- Face the student when talking in order to provide both visual and auditory cues
- Keep classroom noise to a minimum
- Encourage all students to speak clearly in order to provide models for those with speech disorders
- Do not overemphasize speech patterns for the student. Not only does this draw attention to the speech difficulty, but it may actually distort speech.
- Do not speak louder than necessary; use a natural intensity and pitch, with normal intonational patterns
- Reduce the pressures on the student to speak, for example, by lowering the requirements for oral reading
- Give students with speech disorders, who wish to be involved in oral presentations or activities, a chance to practice individually before facing the entire group. Allow them to use visual materials, overhead projector or power point, in their presentations
- Use activities such as debates and panel discussions, dramatization, role playing, reporting, and practice telephone conversations
- Reinforce newly acquired skills from therapy sessions

Augmentative Communication

Many people who are unable to speak at all, or who have speech that is not functional for their needs, communicate by use of augmentative communication. This may include *unaided* augmentative communication (facial expressions, or hands for signing), or *aided* systems (communication boards, synthesized speech systems, or computers).

Teachers whose class includes students using augmentative communication aides may find the following guidelines helpful:

- Consider the student's potential rather than the limitations of the disability
- Inform yourself about the types of devices that the student is using such as Blissymbolics, a Canon Communicator, or Signed English
- Become an active part of the multidisciplinary augmentative team who work, when feasible, with both the student and his parents
- Take time to feel comfortable conversing with the student and to observe their individual methods of communication apart from augmentative communication
- Give the student non-verbal assignments and responsibilities
- Do not let the student capitalize on her disabilities; as far as possible, treat her as you do any other member of the class and expect similar behavior
- Provide the student with opportunities to participate in groups and interact with other class members
- Provide many opportunities for oral experiences in the classroom, such as group singing in which the student signs as other sing

- Inform yourself of the student's special needs in print communication. Is he able to turn pages, write, take notes, and so on. If not, find ways to get around this. Have other students take notes using carbon paper, or photocopy their notes for him.
- Teach the other students about his methods of communication. They can, for example, learn what the symbols mean on a communication board, learn some signing, become familiar with the communication aid, and recognize idiosyncratic means of communication. Have a word, or phrase of the day, that everyone in the class learns.

Teaching Students who are Dysfluent

(THOSE WHO SPEAK WITH A STUTTER OR STAMMER)

~ DO ~

- Become adjusted to the student's dysfluency and react unemotionally and objectively
- Create an atmosphere of ease and relaxation
- Use the student's written work as a measure of achievement
- Make visitors in the classroom—aides, student teachers, or volunteers—aware of the problem
- Listen to the student
- Look at the student's eyes, not lips, during speech
- Praise the student's strong points, such as nice handwriting or good manners
- Provide opportunities for choral reading
- Phrase questions in such a way that they only require short answers
- Divert the student's attention to something else after a particularly bad speech block
- Allow the student to complete a sentence without prompting
- Assign the student duties in the classroom that do not require speech responses
- Allow the student to tell stories, to recite verses, and to read aloud in relaxed situations, and encourage participation in dramatization activities

DON'T

- Show impatience, embarrassment, or boredom
- Use rapid speech, loud commands, or strict discipline
- Excuse poor work or misconduct because of speech problem
- Label the student a stutterer
- Speak for the student
- Make an issue of speech
- Tell the student to start again, or take a deep breath, or any other such help
- Have the student engage in activities, such as speed drills, that only increase dysfluency
- Praise the student for fluency
- Penalize the student when an abnormality occurs
- Try to change the student's handedness
- Show sympathy or pity

—Taken from *Closing the Gaps* by MARGARET WINZER

Like Me

By Emily Kingsley

I went to my Dad and said to him,
There's a new kid who's come to my school.
He's different from me and he isn't too cool.
No, he's nothing at all like me, like me,
No, he's nothing at all like me.

He runs in a funnyish jerkyish way,
And he never comes first in a race.
Sometimes he forgets which way is first base,
And he's nothing like me, like me,
No, he's nothing at all like me.

His face looks kind of different from mine,
And his talking is sometimes too slow.
And it makes me feel funny,
And there's one thing I know:
He is nothing at all like me, like me,
No, he's nothing at all like me.

And my father said, "Son I want you to think
When you meet someone different and new,
That he may seem a little bit strange, it's true,
But he's not very different from you, from you.
No he's not very different from you."

Well I guess, I admitted, I've looked at his face;
When he's left out of games, he feels bad.
And when other kids tease him,
I can see he's so sad
I guess that's not so different from me, from me,
No, that's not very different from me.

And when we're in Music, he sure loves to sing.
And he sings just like me, right out loud.
When he gets his report card,
I can tell he feels proud,
And that's not very different from me, from me,
No, that's not very different from me.

And I know in the lunchroom he has lots of fun;
He loves hot dogs and ice cream and fries;
And he hates to eat spinach and that's not a surprise,
'Cause that's not very different from me, from me,
No that's not very different from me.

And he's always so friendly, he always says Hi,
And he waves and he calls out my name.
And he'd like to be friends and get into the game,
Which is not very different from me, from me

No I guess that's not different from me.

And his folks really love him. I saw them at school,
I remember on Open School Night.
They were smiling and proud and they hugged him real tight,
And that's not very different from me, from me,
No that's not very different from me.

So I said to my Dad, Hey you know that new kid;
Well, I've really been thinking a lot.
Some things are different . . .
And some are not . . .
But mostly he's really like me, like me,
Yes, my new friend's . . . a lot . . . like me. ~

⁂

Emily Kingsley is an Emmy Award-winning television writer (*Sesame Street, The Dick Cavett Show*) who has worked for the rights of disbled children. She has raised a child with Down Syndrome.

Section 3

Equipment

Communication Devices

Having the right communication technology allows a student to truly express himself or herself, and it allows others to see that there is so much more going on inside than meets the eye.

— OCCUPATIONAL THERAPIST VIVIANNE quoted in *Everyone Belongs in our Schools* (British Columbia Association for Community Living)

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Students who have difficulty communicating verbally may need to use other communication methods called technical augmentative and alternative communication (AAC). The term augmentative and alternative communication is used to describe expressive communication methods other than verbal speech, for example, sign language, gestures, and alphabet or picture systems. These AAC systems also include voice output communication aids (VOCAs).

WHO IS AUGMENTATIVE AND ALTERNATIVE COMMUNICATION FOR?

An AAC system can be used by non-speaking individuals who are:

- Physically involved but cognitively able
- Multiply involved with unknown cognitive abilities
- Physically able: dispraxic, language delayed
- Pre-verbal or emergent-verbal
- Autistic

- Developmentally delayed
- And/or have behavior disorders related to inability to communicate effectively

ADVANTAGES OF USING AN AAC SYSTEM

Using an AAC system, students who are non-verbal will be able to:

- Exercise control of their lives
- Develop independence
- Interact with others and express their wishes
- Become productive, active members of society

PROCESSES IN PLACE FOR THE SELECTION AND SUPPORT OF STUDENTS WHO USE AAC TECHNOLOGY

Students who use AAC technologies are supported by their school-based teams who work collaboratively with SET–BC, a Ministry of Education Provincial Resource Program which assists school districts in British Columbia in meeting the technology needs of students with physical disabilities, visual impairments, and autism. The key steps in the process of matching student need to technology, planning, implementing and following-up on student use of AAC technology are as follows:

Stage 1: The child's need for AAC aid is identified by the school team.
Stage 2: The team plans the best-suited AAC device for the child based on his/her needs.
Stage 3: The team implements the AAC device.

WHAT ARE THE DIFFERENT ACCESS METHODS AVAILABLE TO STUDENTS WHO USE AAC TECHNOLOGY?

The term *access method*, describes how the student will select the messages he or she wishes to communicate. This is determined by the student's motor abilities and physical limitations, together with information on fatigue levels, vision and hearing.

Access Methods

DIRECT SELECTION

The student points to, or directly touches, the message or symbol representing the message. Direct selection is a preferred access method, because it is relatively simple and quick. Eye pointing is also a form of direct selection. An eye-gaze board, or *e-tran*, can assist with eye pointing. The student gazes at symbols that are attached to a transparent frame in order to make a selection. The communication partner *reads* the eye-gaze from the other side of the frame.

ASSISTED DIRECT SELECTION

The student may use a body part such as a finger, or a tool such as a light pointer or joystick for direct selection.

VISUAL SCANNING (FOR ELECTRONIC COMMUNICATION AIDS)

Message choices are illuminated electronically, one at a time, by a moving cursor. The student selects the desired item by activating a switch when the choice is illuminated. This access method may be appropriate for the student with motor control problems, giving him/her the ability to accurately select a message from many choices. However, scanning can be slow, as the student must wait for the cursor to move to his/her selection.

LISTENER ASSISTED SCANNING

This access method is useful for students with both motor and visual challenges. In a non-technical system, the communication partner reads out each choice in a predetermined, consistent pattern. The student indicates when the desired selection has been spoken. This can be a powerful access method in classrooms where peers have been given training.

AUDITORY SCANNING

When using auditory scanning with electronic communication aids, messages are quietly read out upon activation of a switch. The student presses the switch again when the desired message is heard, and the message is repeated at a higher volume (Locke and Levin, 1999).

VOICE OUTPUT COMMUNICATION AIDS (VOCAS)

SINGLE MESSAGE DEVICES

The curriculum uses for single message devices are:

- Greetings
- Comments
- Repeated line books or songs
- Telling a joke

Some features of single message devices are:

- Used for student inclusion and participation
- Easily programmed and reprogrammed for a variety of curriculum situations
- Can be pressed directly or used with a switch
- Battery operated and portable
- 20–75 seconds of digitized speech

Some examples of single message devices are:

- BIGmack Communication Aid, AbleNet, Inc.
- One-Step Communicator, AbleNet, Inc.
- Step-by-Step Communicator, AbleNet, Inc.
- Auditory Cueing Communicator, Enabling

MULTIPLE MESSAGE DEVICES

The curriculum uses for multiple message devices are:

- Classroom routines
- Literacy activities
- Answering questions in class
- Social communication

Some features of multiple message devices are:

- Increases independent communication and participation in a range of activities
- Learning to sequence two or more symbols when communicating
- Have potential for up to 40 messages
- Used with one or more overlays, for thematic or spontaneous communication
- Size and number of message keys utilized may be chosen within device boundaries
- May accommodate optical head pointers or switch users with auditory prompts

Some examples of multiple message devices are:

- GoTalk, Attainment Company, Inc.
- Hip Talk, Enabling Devices
- Partner 4, Empowering Resources, Inc.
- Tech/Talk, Advanced Multimedia Devices, Inc.
- Tech/Scan, Advanced Multimedia Devices, Inc.
- Voicepal Pro, Adaptivation, Inc.

DYNAMIC DISPLAY DEVICES AND SOFTWARE

Dynamic display devices refer to computer technology that displays vocabulary using picture symbols or text. When a student activates certain symbols, the display on the screen changes electronically and provides the student with a new set of symbols and messages. The symbols, messages and displays are programmed and can be modified to cater to each student's needs.

In contrast, traditional augmentative communication uses static displays or paper overlays to display vocabulary, which need to be changed manually.

Both types of devices however, provide a voice-output system that the student can use when a vocabulary item is selected. For more information vocabulary selection methods, refer to the section *Access methods available to students who use AAC technology*.

The curriculum uses for dynamic display devices are useful in any activity at school or at home. Some features of dynamic display devices are:

- Access more symbols by changing display
- Multiple access methods including mouse, joystick, touch screen, switch, head pointer, etc.
- Varying degrees of portability

To use a dynamic display device, students need to be able to:

- Recognize pictures and/or auditory prompts
- Remember what messages are available on various displays
- Remember the message they wish to construct when moving through the displays

Some examples of dynamic display devices are:

- Speaking Dynamically Pro, Mayer-Johnson, Inc.
- Writing with Symbols 2000, Mayer-Johnson, Inc.
- Dynamo/DynaVox/DynaMyte, DynaVox Systems
- SpringBoard, Prenktke Romich Company

- Tablet Enkidu, Enkidu Research
- Clicker 4, Crick Software

ICON SEQUENCING DEVICES

The icon sequencing device is an inclusion system that is based on the concept that a finite group of symbols can represent more than one concept based on the order in which they are combined. Minispeak is currently the most common icon sequencing system.

Some features of icon sequencing devices are:

- Message depends on the sequence of use
- Multiple access methods including the keyboard, optical light pointer, joystick, mouse, infrared light pointer or switch activated scan (both visual and auditory)
- Can combine both icons and text in the message display
- Synthesized and digitized speech (digitized only for SpringBoard)

The student learning an icon sequencing system needs to understand the following:

- Concept associations
- Objects and their functions
- Part/whole concepts
- Category associations
- Rhyming associations
- Look-alike associations
- Multiple meanings for the same icon
- Icon sequences
- How to spell a word when the icon sequence does not exist

Some examples of icon sequencing devices are:

- Pathfinder, Prentke Romich Company
- SpringBoard, Prentke Romich Company
- Vanguard, Prentke Romich Company
- Vantage, Prentke Romich Company

TEXT-TO-SPEECH DEVICES AND SOFTWARE

Text-to-speech devices are used to generate synthesized speech by typing in words, letters or sentences. This method of communication can be time consuming and tiring for the students, however, some encoding strategies could be devised, for example, dr. for doctor.

Since students devise their own phrases, text-to speech systems can be used in any activity.

Some examples for text-to speech devices and software are:

- DynaWrite, DynaVox Systems
- Enkidu Handheld, Enkidu Research
- LightWRITER, Zygo
- Link, Assistive Technology, Inc.

Mobility Devices and Transportation

ADAPTIVE EQUIPMENT AND MOBILITY DEVICES:

- Wheelchairs (manual, power and sports)
- Scooters
- Specially made bicycles and tricycles
- Walkers and crutches

PUBLIC TRANSPORTATION AND MOBILITY

HOW ACCESSIBLE IS PUBLIC TRANSPORT FOR A CHILD WITH A WHEELCHAIR?

The SkyTrain, SeaBus, West Coast Express, B-Line bus, and community shuttle minibuses are fully accessible. Most buses have either *low-floor* access or are *lift-equipped*.

USING YOUR WHEELCHAIR OR SCOOTER ON THE BUS

Each accessible bus can carry two wheelchairs or scooters. Though a route is designated as wheelchair accessible, not all buses and/or bus stops may be accessible. Published schedules indicate which runs are not accessible. For more information about bus schedules and accessible bus stop contact Customer Information at 604 953 3333.

Dimensions of Wheelchairs or Scooters that can be used on the Bus

Length: 122 cm (48 in.)
Width: 61 cm (24 in.)

These dimensions include all add-ons such as bumpers, wheelbars,

baskets etc. Three wheel scooters (in these dimensions) may fit *but* some 4-wheel scooters will not due to a wider turning radius. For more information call 604 264 5420.

USING YOUR WHEELCHAIR OR SCOOTER ON THE SEABUS

SeaBus terminals have wide doors allowing mobility devices (wheelchairs, scooters, or someone using crutches) easy access. For information on training to use your mobility device on the SeaBus, call 604 264 5420.

USING YOUR WHEELCHAIR OR SCOOTER ON THE SKYTRAIN AND WESTCOAST EXPRESS

SkyTrain stations and trains are designed for the safety and comfort of passengers using mobility devicess. The West Coast Express is also fully accessible to people with disabilities. HandyPass holders are entitled to concession fares on the West Coast Express. For West Coast Express information call 604 683 7245.

USING HANDYDART

HandyDART is a public transit service that uses specially equipped vehicles designed to carry passengers with disabilities who are unable to use public transit without assistance. Passengers are picked up from outside their residence and dropped off to the outside door of their destination. A person can request a trip by phoning the local HandyDART operator.
The wheelchair lifts on HandyDART vehicles can accommodate devices that fit within the following measurements:

Width: 99 cm (39 in.)
Length: 122 cm (48 in.)
Weight: 250kg (550 lbs.*)

* when the device is occupied and includes the HandyDART driver

TRANSPORTATION FUNDING

The Ministry of Education supports and funds transportation of students to and from instructional programs, which includes the transportation of students with special needs. Each district is authorized to provide these services directly, by contract, or by payment of a transportation allowance:

- Regular transportation
- Special transportation
- Transportation assistance to parents who drive their children
- Transportation for curricular, co-curricular, extra-curricular, and assessment activities
- Transportation between school and home for out-of-district students enrolled in Provincial Resource Programs
- Special equipment to make transportation services accessible. Buses that will transport students with physical disabilities may require the installation of hydraulic lifts

NON-PROFIT ORGANIZATIONS THAT LOAN MOBILITY DEVICES

Organization	Mobility Equipment	Eligibility Criteria	Funding Source
ALS Society	Mobility Equipment	Equipment is offered to those unable to obtain it from any other source	Fundraising
Muscular Dystrophy Canada	Recycled scooters, manual and electric wheelchairs	Financial need	Fundraising
Multiple Sclerosis Society	Mobility equipment. Equipment may be loaned for 12 months or purchased outright.	Be a resident of BC, have a medical professional's the need for the equipment; have limited or no other program eligibility	Fundraising, Private Donations, Bequests, BC Government
Red Cross Society (Medical Equipment Loan Service)	Crutches, wheelchairs	Equipment on loan for up to 3 months	Donations from service users
Red Cross Society (Aids to Independent Living Program)	Wheelchairs, scooters, walkers, lifts	Equipment on loan for those referred by an OT. Financial need must also be demonstrated.	Contracted service through the health authorities

Daily Living Aids

KITCHEN AIDS

Various kitchen appliances have been devised to assist people who have difficulties with food preparation tasks such as paring, slicing, chopping and cooking. These appliances include:

- Cooking utensils
- Dishwashing aids
- Domestic appliances
- Food preparation aids
- Housecleaning aids
- Tables
- Tableware and cutlery

some specialty items can be bought at medical/surgical outlets.

BATHROOM AIDS

Items that can be used in the bathroom to minimize the risk of slipping, falling or getting stuck:

- Bathing aids such as rubber mats, safety treads on the bathroom floor, grab bars, tub rails, etc.
- Bath lifts
- Showers
- Bath and shower transfer seats
- Toilets and toilet seats

HOUSEHOLD AIDS

A number of household aids have been devised to make independent daily living easier for people with disabilities. These include:

- Plumbing fixtures
- Lifting devices
- Grab bars
- Storage
- Telephone adaptations
- Ramps
- Lifts
- Door openers and closers
- Computers

PERSONAL CARE AIDS

This refers to aids that assist people with daily tasks such as shaving, hair- and teeth-brushing etc. These aids fall under the following categories:

- Clothing and footwear
- Grooming
- Walking
- Reading
- Dressing

FINANCIAL ASSISTANCE

Most provincial ministries of health and social services provide assistance to people with disabilities for certain devices and home modifications. This is done through cost-sharing programs between each provincial ministry and the federal government. For more information on the programs available contact:

- Your local branch office of the ministry of health, social services, and/or housing
- A social service worker or welfare caseworker
- Your municipal government or city hall
- A rehabilitation center, hospital or clinic

Educational Aids

Students with complete or partial lack of motor control often have difficulties with gross and fine motor functions such as writing, dressing, buttoning, tying, doing puzzles and working with small objects. Due to these physical limitations, a number of assistive technological aids are used to support instruction.

WRITING AIDS

- Adapted paper (e.G. Raised lines, highlighted lines etc.)
- Pencil or pen with adaptive grip
- Type writer
- Portable word processor
- Computer

ALTERNATE COMPUTER ACCESS

- Enlarged keyboards
- Voice recognition software
- Word prediction (e.g. Co: writer) to reduce keystrokes
- Keyguard
- Track ball, track pad, joystick with onscreen keyboard
- Alternate keyboard (e.g. Intellikeys, Discover Board, TASH)
- Mouth stick or head pointer with standard or alternate keyboard
- Head mouse or head master/tracer with onscreen keyboard

WRITTEN COMPOSITION

- Word processor with word prediction (e.g. Co: writer) to facilitate spelling and sentence construction
- Talking word processor for multisensory typing

VOICE RECOGNITION SOFTWARE

- Word cards, word book, or word wall
- Electronic or talking electronic dictionary, thesaurus, or spell checker (e.g. Franklin bookman)
- Word processor with spelling and grammar checker, pocket dictionary or thesaurus

READING, STUDYING AND MATH AIDS

READING

- Scanner with talking word processor
- Use of pictures with text (e.g. Picture It, Writing with Symbols)
- Changes in text size, spacing, colour, or background colour
- Book adapted for page turning (e.g. page fluffers, 3-ring binder, cardboard in page protector)
- Electronic books

LEARNING

- Software for manipulation of objects or concept development (e.g. Blocks in Motion, Toy Store)
- Print or picture schedule
- Highlight text (e.g. markers, highlight tape, ruler)
- Low tech aids to find materials (i.e., index tabs, color coded folders)
- Recorded material (books on tape, taped lectures with number coded index)

MATH

- Calculator with large keys or large LCD print out
- Talking calculator
- On screen calculator
- Abacus or math line
- Software with templates for math computation (consider adapted input methods)
- Tactile or voice output measuring devices (e.g. clock, ruler)

VISUAL AIDS

- Magnifier
- Screen magnifier (mounted over screen)
- Screen magnification software (e.g. Closeview, Zoom Text)
- Braille keyboard and note taker (e.g. Braille N Speak)
- Braille translation software
- Large print books
- Screen color contrast (e.g. CloseView)

HEARING AIDS

- Classroom amplification
- Screen flash for alert signals on computer
- Captioning
- Signaling device (e.g. vibrating pager)

RECREATION AND LEISURE AIDS

- Universal cuff to hold crayons, markers, or paint brush
- Ergo rest to support arm for drawing or painting
- Drawing or graphic program on computer (e.g. Kid Pix, Blocks in Motion)
- Modified utensils (e.g. rollers, stampers, scissors)

Classroom Etiquette & Tips

WHEELCHAIRS

The wheelchair becomes part of the body-space of its user. Except in emergencies other people should not move the chair without the consent of the person to whom it belongs. Nor should the chair be used as a "leaning post" by other people.

CRUTCHES, CANES AND WALKERS

The tips of crutches, canes, and walkers should be kept clean and dry. They can become very slippery if they get wet. Teach your students to wipe up any spills in order to prevent accidents fro their classmate who uses these mobility aids. If the tips get wet outside, be sure they are dried off before the student walks on smooth-surface floors.

ELECTRONIC COMMUNICATORS

All children who use an electronic communicator should also learn, and have available to them, other systems in case of a power failure.

HEARING AIDS

Hearing aids pick up all sounds and amplify them equally, so environmental noise should be kept to a minimum. I(f there is noise from a fan, an air conditioner, or a film projector, the student using a hearing aid should sit as far away from it as possible.

Whatever the task, there is equipment that may make it easier for your student to learn to live independently. Discuss his/her needs with the therapist on the team.

ADAPTING SURFACES FOR READING & WRITING

If a lack of coordination, tremors, or other physical disabilities keep your student from holding the writing paper in place, tape it down with masking tape.

A number of stabilizing materials and techniques can be made or purchased from many stationery supply stores.

STANDARD CLIPBOARD: A clipboard is useful for general writing when the child needs help stabilizing one or both hands.

ONE-HANDED WRITING BOARD: This board is lever-operated. Clamps hold the paper on the board and rubber feet keep the board from moving. The board is available for right or left handed students.

NON-SKID PLASTIC: This material is available in sheet form or pieces of various sizes. It is excellent for holding a clip-board steady, or for stabilizing equipment such as dishes in the cafeteria or the cooking lab.

TILTED DESK: This slanted work surface can rest on table or wheelchair tray.

OVERHEAD BOOK HOLDER/EASEL: This easel has an adjustable knob that locks support arms in position to hold up to 30 pounds. Elastic straps hold books, magazines, or note pads.

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DAILY LIVING AIDS

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ADDITIONAL RESOURCES

About agencies and programs in British Columbia that provide support for school-age students who use augmentative communication systems:

http://www.setbc.org/setbc/communication/communication_library.html, Communication Library, Augmentative and Alternate Communication (AAC) Services in British Columbia (2005)

About product information on AAC Technology: *ftp://ftp.setbc.org/pub/pdf03/aac_tech.pdf*

About a listing of selected vendors of AAC technology: *http://www.lburkhart.com/sr.htm*

Section 4

Lifetime Transitions

Lifetime Transitions

Throughout our lives we make many transitions. For people who may need special supports, it is advisable to make sure that those supports and services are in place ahead of time. By ensuring that the student has all the supports he/she needs, the stress level of everyone concerned will be reduced. This section will describe some of the transitions in the life of a student with a disability, and how the school system can make these changes less stressful for everyone involved.

THE YOUNG PERSON AND THE STARFISH

a story inspired by Loren Eiseley

A woman was taking a sunrise walk along the beach.

In the distance could be seen a young person
who seemed to be dancing along the waves.

As she got closer she saw that the young person was
picking up starfish from the sand
and tossing them gently back into the ocean.

What are you doing? the woman asked.

The sun is coming up and the tide is going out;
If I don't throw them in they'll die.

But there are miles and miles of beach with starfish all along it—
you can't possible make a difference.

The young person bent down, picked up another starfish,
and threw it lovingly back into the ocean,
past the breaking waves.

It makes a difference for that one was the reply.

TRANSITION INTO KINDERGARTEN

Transition from preschool programs to kindergarten is a milestone in a child's development. A successful transition doesn't happen in one day, but evolves through a process of cooperative planning and decision-making. In early intervention we are seeing more and more attention paid to the issues of transition, and the emergence of transition teams and transition plans. Parents and professionals are serving as advocates for developing positive and typical opportunities for children with special needs as they become of kindergarten age.

All children should have the option to enter their neighborhood school for kindergarten or first year of public school. For children with special needs, special education services may or may not be critical for successful inclusion, but should never be a roadblock to it.

Special education support may be important in the following areas: peer integration and support, teacher information and resources, specialized transportation, mobility and pre-braille training, alternative communication, assisted technology, speech therapy, self-care, nursing care with a gastrectomy or tracheostomy, adaptive physical education, occupational or physical therapy, and behavior management. Any or all or these services can be integrated into a child's whole kindergarten program if a true collaborative spirit and partnership exists between children, families, and professionals.

One thing we must do as a child gets ready to turn five, is listen to the family. What are their plans, dreams, needs, fears, values and perceptions? What do they want for their child and themselves? What do they want from you and other professionals at this stage? We must respect the family's opinion and support their decision making process; a process made more difficult by a multitude of service delivery options. These services may range on a continuum from segregated special day classes to full inclusion with support services before, during, or after the regular kindergarten program.

We must keep challenging ourselves to seek creative alternative possibilities to meet these children's needs in our educational systems and communities.

Another critical issue to explore at this time, is the child's social opportunities and peer interactions. Inclusion is not just having your own carpet square spot in the morning circle, but having friends, peers and adults who care about you and want to be with you. Take the time to explore with families all of the experiences a child is having in the community. If there are barriers to typical opportunities, what can be done to eliminate them? So much can be done when caring people come together determined to make things work! For example, if a family can't attend church because no one in the nursery knows how to care for their child, certainly some education and training can be done. Public or private school teachers may come and go in a child's life, but their church members or other community friends may remain with them for years. You should know that positive steps are being taken to support each child's socialization in his/her community during the transition to kindergarten.

A final consideration at this time is our communication with the child. It is important that we prepare him/her for this transition, too. Transition research at the University of Kansas at Lawrence, found that child preparation activities should include such things as providing opportunities for the child to make new friends, care for their own possessions and personal objects, share their toys with others, use books, be as independent as possible in their self care, ask for assistance when needed, and follow directions and routines. Activities with siblings in preparation for this transition may also be appropriate.

The hard part will be to gain the commitment of all those involved with the child at the age of five to make this time of transition family-centered, community-oriented and a true parent/professional partnership. ~

—Reprinted from *Community Integration*, published by
The Queen Alexandra Center for Children's Health

TRANSITIONS—BETWEEN SCHOOLS

Whether it is between two schools at the same level, or going from elementary to secondary school, this period of transition can be very stressful for everyone concerned. The following suggestions, gleaned from the experiences of others who have traveled this road, may help reduce the stress and make the transition smoother:

- Start planning for the transition well in advance
- Keep the focus on the student, and how the system can meet their needs. This must be a cooperative effort between the student, parents, present and future teaching staff (classroom, resource room, special educators, assistants) and other support persons (therapists, etc.).
- The student should visit their new school where they will be given the opportunity to attend a class, learn where the different classrooms and facilities are, and meet the staff who will be working with them. If possible, the classroom teacher and assistant, who will be primarily responsible for the student following the transition, should visit the present classroom, so that they can see how the student relates to the teacher and other students.
- If the new location has lockers, with combination locks, let the student take his lock home for a few days to practice using it
- If the student has friends in the new location, suggest that they invite him/his to accompany them to social events prior to the transition
- Ask different students to volunteer to be 'buddies' for specific tasks—a locker buddy, a street-crossing or bus buddy, a lunch-time buddy, a PE buddy—until the student can master the skills to do these things independently
- Make sure that his/her classmates understand the student's disability, the challenges involved, any special equipment being used, and how they can make things more pleasant for everyone by their attitude ~

BEYOND SECONDARY SCHOOL

Planning for the transition from secondary school into the future should start at least *three years* before it is due to take place.

There are many things to consider. As with any student, interests and abilities are the primary considerations in this planning. For the student who will need special supports, there are other things to keep in mind and prepare for.

Help your student be realistic in making plans. Maybe the ideal career that he/she has in mind is an 'impossible dream' because of physical or intellectual limitations, but there are probably allied careers that would be possible. For example, it may not be feasible for a person with a speech impairment to be a speech pathologist, but becoming a receptionist in a clinic might be an acceptable alternative.

Where can your student go for career counseling and training? Every community college and university in BC has someone responsible for students who need special supports. Your student should make contact with this department in his/her chosen facility at least a year ahead of planned enrollment. Many of the colleges offer special trade training and/or career exploration programs for students with disabilities.

It is very important for the student who will need special supports in post-secondary schools to learn self-advocacy skills. He/she must be able to let people know what his/her needs are in the ways of special material, assessment procedures, and extra time.

There are many resources available to help a student plan for their future. They should contact their local library or the association specializing in their particular health challenge.

If the use of a computer would help your student become more independent, check out the Neil Squire Foundation, whose mandate is to develop methods and programs that make it possible for *anybody* to access the computer.

FUTURE LIVING ARRANGEMENTS

Many young people continue living with their parents, at least part time, until they are established in their careers. People who have disabilities sometimes stay there indefinitely, often because there seems to be no viable alternative.

The longer they stay, the more dependent they become, and the harder it is for them to move on into independence. Consequently, there are individuals with disabilities who are still living in the family home as middle-aged people, still dependent on their elderly parents to make their decisions and plan their lives. In most cases, this is an unhealthy situation for everyone concerned. The parents need to get on with their own lives, enjoying freedom that has been denied them during the earlier years. Eventually other accommodation is going to have to be found, and it is easier and less traumatic for the young adult if this is done while the parents are still able to actively assist in the transition.

There are a variety of options, depending primarily on the level of support needed. For those who need extensive assistance with daily living, a group home or private boarding home may be the best answer. For those who can look after their own personal needs, but need help with housework and cooking, the Ministry of Health Long Term Care program may provide homemaker assistance. To access this service, phone your local Health Authority and ask to speak with the Community Care or Home Care Intake Worker. Sometimes two or three people who each need this assistance can arrange to share accommodation, thus pooling their allowable homemaker hours. In some situations, the Ministry hires and finances this assistance directly; in others, where the person has the skills or support needed, the money to pay for these services is paid over to the individual who is then responsible for arranging his own care needs. This latter plan works best if there is a *circle of friends* willing to oversee and assist with the arrangements.

HOUSING OPTIONS

HOUSING CO-OPS

For a complete listing of Housing Co-ops accepting applications contact the Co-operative Housing Federation of BC:

web: www.chf.bc.ca
phone: 604 879 5111
toll free: 1 866 879 5111

GROUP HOMES OR SUPPORTIVE LIVING

You need to contact your local Health Authority (found in the blue pages of the phone book, or Google Health Authority) and speak with someone in Home Support Services.

CSIL

For information on the CSIL (Choice in Supports for Independent Living) program, which allows individuals direct funding to purchase personal attendant services, contact your local Health Unit and ask for an application package.

AFFORDABLE RENTAL HOUSING

Find rental listings in the lower mainland area from Hope to Whistler at www.partnersinhope.ca/housing-search

REALITY VERSUS DREAMS

A teenager who needs forearm crutches and has impaired speech wants to be cruise director for a luxury liner.

A young man who cannot fathom simple mathematical concepts dreams of becoming an accountant like his father.

A girl who is legally blind hopes to be a dress designer.

We all know of people like the baseball pitcher with one arm, the football player who kicks the ball with only half a foot, the man born without arms who uses his feet to play the drums. These people have realized their dreams, but they are extraordinary people with unusual determination. Most of us, even with no identifiable disability, cannot do everything of which we dream. We must prepare for the realities of our lives, while still holding onto those dreams.

Young people who have disabilities often have trouble discerning their dreams from their realistic potential. They need the help of people around them to make these distinctions.

As part of their career discovery process, have them talk or write to someone who is in the vocation they are attracted to. Rather than telling them they can't do something, let them find out the realities of what is involved, and what the requirements are. Maybe in so doing, they will find allied occupations more suited to their abilities.

Sometimes the adults in their lives decide that 'he will find out his limitations for himself soon enough; he doesn't need to hear it from me.' The result of this thinking can be a young adult who is severely—even suicidally—depressed when he discovers that there are limitations he had been led to believe did not exist.

Don't discount career possibilities that could be enabled by adapted equipment or special training. There are numerous possibilities for fitting

the job to the individual, through workplace or equipment adaptations, job coaching, or training programs, and there are people who specialize in advising both potential employers and employment candidates of how his needs can be met. Listings of just some of these are included in the Resources section of this manual.

FINANCES

Nobody gets rich being disabled! If one is able to work, he is expected to do so. In the real world, there is a lot of unemployment of even the most qualified and able people. Most employers have their choice of numerous applicants for every position available. It is only natural that in most cases they are going to take the easy road, and hire the person who is apparently the most able. There are specific job-sites, principally governmental, where there is a requirement to hire a certain proportion of people who meet criteria based on race, gender, or physical or mental disability.

The reality is that the majority of people with disabilities do not find employment, so they remain dependent on either their families or the government.

BC Disability Benefits provides a basic allowance, far below the poverty line, on which the person with a disability is expected to live. On top of that basic allowance, there can be a per month shelter allowance, the exact figures change from time to time. If the individual can find subsidized housing, this is the amount that they would be required to pay for rent and utilities. If they cannot find subsidized housing, (there is a very limited supply, especially outside the metropolitan areas), then they must rely on their families or friends, or go into group living situations.

An individual on BC Disability Benefits receives most of their medical and dental coverage. They are also entitled to a low cost bus pass as well as reduced prices on many services, such as community recreation programs and transportation.

SEXUALITY AND DISABILITY

The important subject of sexuality is often ignored by parents and professionals. Many people are uncomfortable talking about sexuality and may see the teenager with chronic illness or disabilities as a non-sexual being.

It is a myth that children and young people with chronic illness and disability are asexual. Parents and professionals may avoid talking about sexuality. Societal attitudes may prevent experiences and opportunities that are similar to those teens without disabilities or illness. This does not take away feelings and thoughts. It can only add to the concerns.

People with disabilities are extremely vulnerable to abusive situations. They may be physically unable to remove themselves from uncomfortable situations. They may not be able to understand and evaluate innuendo and suggestive comments. They need all the same information that is needed by everyone else at their age. Those with limited understanding must have this information geared to their level of comprehension.

Children with developmental delays may have reduced inhibitions, and need to be instructed in what is appropriate behavior. Without being judgmental, they can be taught to differentiate between *private* and *public* behavior. It would be best for teachers to discuss this with the parents, so that the child is not getting mixed messages. There are some excellent books available on this topic; sharing one of these may make the discussion easier to initiate with the parents.

Students who are physically dependent on caregivers for personal care must have someone with whom they can confide. If their speech is affected, they may not have the vocabulary to express what is happening to them.

For information on all aspects of sexuality as it concerns children with disabilities, contact the Sexual Health Resource Center, sponsored by Sunny Hill Health Center for Children. This service has an extensive library of books and videos for loan throughout the province.

STRATEGIES FOR INCLUDING PARENTS IN TRANSITION PLANNING

TRANSITION PLANNING

Transition planning develops a vision and designs a plan necessary to realize that vision. Transition planning seeks to prepare the student (with family support) and the new environment by developing a plan that creates a bridge of service and supports for the individual.

> *Effective planning requires the participation of the entire school community, not a single special teach. Effective planning requires actions, and regular monitoring of that action by the school and the family. Monitoring and evaluation should lead to corrective action where needed. If problems do occur, they should be seen as problems of the plan or its implementation, not of the child or the child's performance.*
>
> —*Integrated Education, No More Segregated Settings.* Prepared by MARSHA FOREST and BRUCE KAPPEL.

INCLUDE PARENTS IN TRANSITION PLANNING

- Involve parents in the designing of the protocol or planning process.
- Clarify the mechanics of the plan for the student and the parents through an orientation. The mechanics refers to the timelines the school has established, which are bound by dates for program changes, etc. It also refers to the meetings scheduled to organize a student's programs and put the necessary supports in place—a lot of this can be included in a planning guide for students and parents. Draw out the parents' issues for transition planning and then orient them to the process you are currently

using. Find out if this will work for them and their child. Make necessary adjustments.

- Problem—one of the biggest problems for parents and students is the wait over the summer when no plans can be made and no follow-up can happen. If the student's plan is not in place before the summer, it can be a very anxious time for parents and students.
- Plan—some thought should be given to the first day and the first week of school. Who will greet this student – the assistant, resource teacher, or a peer? Backup plans in case of failure may also be an important feature.
- A Planning Guide—develop a planning guide that outlines the process for transition planning. It can include such things as preparation for graduation.
- Discuss ways that the school and family and the community can prepare the student and the new environment for the transition.
- Prepare a chart to help assess above areas and establish goals and an action plan with timelines. List student's skills (work, social, academic, independent living, etc.); record interests; determine student's needs; note the supports available and those needed; clarify the issues and note the possible barriers.
- Gather and disseminate basic information to parents on services, supports and programs through:
    - A Transition Handbook (consumer's guide to existing options) This can include the planning guide and include an introduction to transitions issues advocacy programs and information pertaining to life after graduation (income assistance, day programs, college options, leisure and recreation, residential options, health care information, etc.)
    - Visiting opportunities where the student-to-be visits the school in the

previous year to begin to make the new environment familiar. Or it might mean visiting day programs, residential options and potential work settings.
    - ▹ Teachers and or counselors should have opportunities to visit the student in his present setting, to meet with the parents, the principal and classroom teacher, and discuss the IEP. Transition meetings are often one-sided. Seldom are there individuals representing the classroom or setting the child is moving from.
    - ▹ In-service transition planning - this is designed for students preparing for graduation. Make a list of potential community and ministry services available, criteria for evaluating them and procedural steps for entry. Ideally parents should be offered this information over a five to six year period. This would allow them to process the information and stay up to date.
- Promoting the Use of Natural Supports
    - ▹ Develop a community inventory (hang-outs/leisure opportunities, recreation programs, extra-curricular school activities)
    - ▹ Look for volunteer opportunities
    - ▹ Join neighborhood associations/groups
    - ▹ Exchange or trade services and favors with families and friends
    - ▹ Participate in peer tutor programs/buddy system
    - ▹ Share stories about how people got their first job (put ourselves in their shoes)
    - ▹ Find a natural solution to a transportation problem
    - ▹ Ask a neighbor for help/helping a neighbor (reciprocity)
- Include parents in the Improvement of Post School Opportunities
    - ▹ Even the most powerful transition plan will flounder if there are limited choices for graduates after they leave school. The expansion

of choices results from ongoing pressure from various interest groups. Parents are key in advocating for these changes.

- Encourage parents to start a Parent-to-Parent Focus and Support Group
  - ▹ The ongoing education of parents about transition issues is most credibly done by parents who have been through it. The objective of ongoing parent education could eventually be the establishment of a parent group dedicated to transition issues. ~

Section 5A

Children with Autism Spectrum Disorders

Autism Spectrum Disorders

"I know things are missing in my life, but I have an exciting career that occupies me every waking hour. Keeping myself busy keeps my mind off what I may be missing. Sometimes parents and professionals worry too much about the social life of a child with autism. I make social contacts via my work. If a child develops his/her talent, they will have contacts with people who share their interests."

—TEMPLE GRANDIN 2003

Autism Spectrum Disorders/Pervasive Development Disorders are umbrella names for the identification of five different disorders:

- Autistic Disorder
- Pervasive Development Disorder—Not Otherwise Specified (PDD-NOS)
- Asperger's Disorder
- Rett's Syndrome
- Childhood Disintegrative Disorder

Autism Spectrum/Pervasive Development Disorder is *not* a disease, but is understood to be a neurological disorder that can affect children's reasoning, social interaction, communication, behavioral concerns and motor development.

COMMON CHARACTERISTICS OF CHILDREN WITH ...

Autism	Asperger's
Concerns in typical development can be noticeable before the age of three	Concerns in typical development can be noticeable in later childhood
Can appear to understand very little or seem deaf	May speak intelligently but not necessarily comprehend what the words mean
May appear unaware of feelings of others—even the child's mother	May appear to lack empathy or connections to others emotions
May use few words or none at all and lack facial expressions	May use one sided conversation and sound monotone in speech
May show signs of dislike towards physical contact, eg. hugs and cuddles	May show anti-social or avoidant behaviors
May line up or shake/spin toys in repetition—often lacks make-believe play	May fixate on specific interests or topics and excel in them, showing lack of interest in typical play
May show sensitivity to light, sound, taste or smell	May show signs of underdeveloped vestibular or proprioception
Can possibly exhibit frequent tantrums in unpredictable situations	May show aggression to self or others when under stress
Shows signs of avoiding eye contact	May not look at the person when speaking to them
A change of routine can produce great anxiety	Dislikes any change to routine as it could produce anxiety
Does not appear to engage or understand social interaction	May fail to develop peer relationships appropriate to their age
May show delays academically compared to classmates	May show delays academically compared to classmates, but may excel in a subject of interest

WHAT IS PERVASIVE DEVELOPMENT DISORDER—NOT OTHERWISE SPECIFIED (PDD-NOS)?

PDD-NOS is a diagnosis given to a child when some of the symptoms of Autism may be present, but the full criteria of the autistic label is not met. The child may have some aspects in the developmental differences of communication, social skills, and sensory development within the Autistic Spectrum Disorders. A child diagnosed with PDD-NOS may show symptoms of hyperactivity, short attention, irregular sleeping patterns, restricted food preferences, difficulty in calming or unexplainable distress. A child with PDD-NOS can generally be more responsive to treatments supporting the child's individual needs.

STRATEGIES AND TECHNIQUES TO SUPPORT A CHILD WITH:	
Autism	**Asperger's**
Very structured daily schedule	Predictable daily routines
Direct one-to-one interaction for learning	One-to-one Peer Buddies for academic and social support
Provide quite low stimulation environments	Provide opportunities for the child to retreat to a low stimulation space
Repetition, predictability and interesting material will hold a child's attention	Use their interests to help motivate the child through difficult activities
Use visual, verbal and physical prompts	Provide opportunities for role playing and modeling acceptable behaviors for the child
Teach social behaviors with an adult, gradually moving the practice with other children	Create a social group for the child
Provide slow gradual change of an environment when progressing a child into new territories	Provide preparation and anticipatory clues when transitioning into change
Involve family, friends and professionals to support consistency across all environments	Involve family, friends and professionals to support consistency across all environments
Written words, pictures and visual schedules are more affective than auditory input	Provide visual and auditory input when communicating requirements

CAUSES

There is no known cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure. Brain scans show differences in the shape and structure of the brain in autistic versus non-autistic children. Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting a genetic basis to the disorder. While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that autistic children may have inherited. It also appears that some children are born with a susceptibility to autism, but researchers have not yet identified what causes autism to develop.

I think my child shows signs of Autism, what can I do?

- Obtain a diagnosis from a professional/specialist
- Make an appointment and take the diagnosis documentation to your nearest Community Living Services office
- See a social worker who will confirm your child's eligibility for funding
- Contact the Ministry of Children and Family Development to obtain a list of community service providers under the funding contract that would best suit your child's needs. A link to the list is available at www.mcf.gov.bc.ca/autism

What are some of the Most Effective Interventions to Autism?

Due to the spectrum nature of autism and its many behavior combinations, no one approach is effective in alleviating children with symptoms of autism, however the following interventions have been found to be helpful:

- Behavior modification
- Speech and language therapy

- Sensory integration
- Vision therapy
- Music therapy
- Auditory training
- Medications
- Dietary interventions, among others

Experience has shown that children with autism respond well to a highly structured, specialized education and behavior modification program, suited for the child's specific needs. A thorough intervention approach will include some level of behavior modification, communication, social skills, and sensory development.

Treatment may also include both social and drug therapy. Family, psychiatrists, behavioral therapists, occupational therapist and general practitioners are components of a supportive team for a child within the Autistic Spectrum.

RESOURCES

The Autism Society of BC
A parent-based and directed society providing support to individuals with autism spectrum disorder and their families in B.C. and the Yukon.
Phone: 604 434 0880 (lower mainland)
Toll Free: 1 888 437 0880
Web: www.autismbc.ca

BC Autism Assessment Network (BCAAN)—Provincial Health Authority on Autism
Information on assessment/diagnosis of children
who may have autism spectrum disorder.
Phone: 604 453 8343
E-mail: autism@phsa.ca
Web: www.phsa.ca/AgenciesServices/services/autism.htm

BC Ministry of Health
Access to an evidence-based report: Standards and
Guidelines for Assessment and Diagnosis of Young
Children with Autism Spectrum Disorder in B.C.
Phone: 250 952 1742
Toll Free: 1 800 465 4911 (in B.C.)
Web: www.healthservices.gov.bc.ca/cpa/publications/asd_standards_0318.pdf

Ministry of Education—Special Education: Autism
Information on special education programs and autism initiatives.
Web: www.bced.gov.bc.ca/specialed/#Autism

Provincial Outreach Program for Autism and Related Disorders
An educational organization to help teachers, parents and para-professionals access information about autism and the B.C. school system's available resources.
Web: www.pop.deltasd.bc.ca/
Sunny Hill Health Center
Web: www.sunny-hill.bc.ca

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A Day in the Life of Isabella— A Girl with Autism

Isabella awakes at 7:30 AM every morning. Her mom assists Isabella in changing into her daily clothes and fresh pull-ups, as she's still working on her toilet training. Isabella flaps her hands happily and giggles eagerly as her mom gives her 20 minutes for puzzle time while breakfast is prepared.

Isabella has an incredible ability to piece together up to 1000 piece puzzles. She intently feels each piece and brings it close to her eyes, sets it aside then, appearing to remember where each one is, she connects the shapes with great focus and delight. At the 15 minute mark mom tells her she has 5 minutes before breakfast. This prepares Isabella for a change in activity. For breakfast Isabella has porridge or pureed fruit as she shows protest to any hard or lumpy consistencies in her food. She communicates this by scrunching up her face, tensing her body and crying.

Isabella goes to morning kindergarten class five days a week where the team has been working on picture symbols for her to communicate with. After school Isabella's 1:1 Worker (through her families Autism Funding) picks her up. With the assistance from the school program the 1:1 Worker incorporates a visual schedule and communication tools. She takes her to Play Therapy, Snozolen Room and a social group. Activities are alternated through out the week and incorporate a visual toilet routine and slow introductions to different food consistencies. She also works on her life skills. Isabella's father arranges to pick her up from the 1:1 Worker at 4:00 PM. Once at home Isabella has an hour of free-time where she can *de-stimulate, self regulate* and retreat into her isolated playtime.

At 5:20 PM dad gives her ten minutes warning that dinner is soon and

again at five minutes allowing her time to anticipate the transition. At 5:30 PM mom comes home from work, dinner is served and dad assists Isabella with her pureed meal. Isabella gives high pitch chirps as she watches the ceiling fan while eating. After dinner Isabella will retreat to her bedroom and play with one of her toys. She loves to spin the wheels on her vacuum popper toy and rapidly shake her Barbie dolls, while intently watching their long hair swish back and forth. After mom and dad have caught up on their day mom starts a bubble bath for Isabella, which she loves and routinely expects. Mom watches over Isabella even though she can do the majority of the routine independently. Isabella is known to drink the bath water or pee in it and will squeal in delight with mom's response.

In the past Isabella would spend entire nights crying, screaming or banging objects keeping the whole family awake. Tests never found any medical reason for this. With help from the pediatrician and an occupational therapist Isabella now takes Melatonin, a natural sleep enhancer, and sleeps with a weighted blanket for the first 20 minutes. She now sleeps peacefully the whole night through and so does the rest of her family. ~

A Day in the Life of Matisse— A Girl with Autism

My daughter's name is Matisse and she is six years old. When she was three and a half years old she was diagnosed with autism. Intuitively, I think I knew when she was two years old that something was wrong, but it was at least a year before I was brave enough to face the reality that she was different.

People often ask me how I knew, and when I think back there wasn't one big indicator, it was a combination of *just a feeling*, and little discrepancies between her and children her age. Matisse didn't talk as well as other children, she didn't seem to understand what I said to her, and often repeated back my own words, or lines from books and movies. She had strange, irrational, and inconsistent fears; sometimes it was people, or a store window display, an exit sign, the vacuum cleaner (and not just the sound, the sight of them would reduce her to tears), and everything new, unfamiliar or unexpected. For example, if I bought a new children's video she would need time to digest it before we could open it. Most of my friend's kids could hardly wait to get the tape into the machine, but Matisse needed to look at it for a couple of days first. If I was able to convince her to watch it she used to stand outside the TV room and peer at the screen from around a corner, one eye closed, and her body rigid and defensive, almost afraid of what was going to happen next. However, once she became familiar with a video, or toy, she demanded it exclusively. She also didn't seem to play with toys like other kids; she preferred to sort and categorize the pieces, either by shape, or colour, or she would line them up end to end like a long train. Playing

looked more like a series of tasks that she tried and mastered, but she never created anything, and never used her imagination. However, my biggest concern, the one thing that weighted the heaviest on my heart, was her disinterest in people, especially her new little brother. All my friends, who were having their second babies at the same time, gushed at how loving, doting and helpful their oldest child was with the new baby. It was a very sad and disappointing time for me—Matisse took no interest in Mason.

Yet, despite all these little idiosyncrasies I still allowed people to reassure me she was fine, and that all children develop at their own pace. Whenever I worried, or voiced my frustrations about Matisse's slow development my friends would tell me how lucky I was that she played so well on her own. When she echoed back my words people often said that children learn through imitation & repetition. On the surface it was reassuring, but deep in the pit of my stomach I knew something wasn't right.

When Matisse still wasn't speaking appropriately by age three I knew it was time for me to face my deepest fears. I finally realized that the only person I was hurting, by being in denial, was Matisse. I knew she needed help, and I needed to find a way to get it for her. I began researching autism (strangely, I had a hunch she was autistic even though I had no experience with the disorder), and I sought out doctors who could confirm my suspicions. It took two speech and language pathologists, two pediatricians, and a developmental psychologist five months to finally make the diagnosis. The first doctors told me to wait until she was five; they said it was too early to tell if she was delayed. I remember thinking, what am I suppose to do with her for two more years! She needs help now, I need help now! On the day Matisse was diagnosed I remember leaving the doctor's office feeling calm, and sort of relieved. For the first time in over a year I felt optimistic about her future. I think I had stopped hoping and dreaming about Matisse's future because I was afraid of what it might look like. Having a diagnosis meant that I could finally access help. I had done a lot of research on different therapy programs, and the day she was diagnosed I took all her diagnostic reports and test scores to an organization that specialized in

Lovaas Applied Behavioural Analysis (ABA) and started the in-take process. One month later she began an intensive treatment program. That was July 2002.

NOVEMBER 2002

By November I felt like we were really in the trenches—so much had happened since starting Matisse's program. Our lives had literally been turned upside down. By late August I had started interviewing and hiring therapists to work with Matisse, in September our behavioural consultant arrived from London and she immediately began programming for Matisse and training up our team of five therapists. We ran three shifts per day; three hours in the morning, three hours in the afternoon, and two more before dinner. It is a long day for Matisse; it was a long day for all of us.

Preparation for each new day had to start the night before. Matisse began everyday at 8:00 AM so I had to make sure her room was tidy (it was also her therapy room) and everything was is order. Each night I'd make sure her manipulatives were sorted; little people, animals, cars, blocks, food, shapes, colours, etc. Her closet had been transformed from a place to put clothing to a small toy store/craft store/office. Every night I'd ensured there was a craft ready to make, the program binder was up to date with new data sheets, program checklists, behaviour tracking sheets, graphs, time sheets, etc., and I'd put together her visual schedule for the next day. A visual schedule is a pictorial representation of her day's activities (who would be coming to the house and what they would be doing). I'd always make sure there was a *surprise* picture symbol just in case I had to make any last minute changes during the day.

Just before Matisse went to bed we'd go over her visual schedule together. This is called *preloading* and it was a tool we used to help Matisse anticipate the next day, so she would know what was expected of her. Matisse required a lot of processing time in order to cope, and without it she became very anxious and overwhelmed. We'd also look over the schedule just before her

day began, and during each transition, our lives were dependent upon this visual schedule.

Like many autistic children, Matisse didn't sleep well. It could often take a couple of hours to get her settled before she'd drift off to sleep, and then she had to be up by 7:00 AM. Once she was in bed the remainder of my evening would be spent making new materials for her program, or keeping up on all the ministry paper work.

In those days 7:00 AM came quickly, and mornings were never fun. Matisse was on a special gluten free, casein free diet, which basically meant no bread and no dairy. It was always challenging coming up with meal ideas that adhered to her diet and what she would eat. Like many autistic children Matisse was a very finicky eater. Most mornings I'd offer her some fruit and a piece of gluten free toast with jam, or gluten free waffles, and most days she'd refuse. I'd have to put it on the table, in front of her, and let her think about it for a while. Dressing Matisse was also a huge challenge; she was tacitly sensitive to clothing and preferred to stay in her pajamas. She was very averse to wearing pants, and only wanted skirts or dresses, however, experience had taught us that she *stimmed* too much, and didn't attend well when she wore them. *Stimming* (short for self-stimulation) means she'd pick and play at her clothing to the point where she wasn't able to attend, or concentrate on anything else. She'd always get upset, and have meltdowns when discovering she couldn't wear a dress or skirt—which was pretty much every morning. She'd drop to the floor crying and screaming, arching her back when I'd try and pick her up, and throw her clothes across the room. Although Matisse spoke words, she didn't understand the pragmatics (usage) of language and therefore couldn't express how she was feeling or what she wanted. Even though I knew it is useless to try and explain, again, why she couldn't wear a dress, the part of me that longed so badly for a *normal* child tried to rationalize with her. My words only frustrated her more because she didn't understand what I was saying to her. When I could finally get close enough to her I'd drop down to eye level and walk her through her

'relax' program (counting and deep breathing), this program was designed to give her some self regulating techniques to help her through tough situations. When she was calm, and had some time to process the morning's expectations, she'd allow me to dress her, and eventually would eat a bit of breakfast. I would go through the visual schedule with her again, this time removing *get up, eat breakfast, get dressed*, and the *go to bathroom* symbols. I'd remind her that Tammy was coming over and would show her the photo of Tammy to give her a mental image, and then I'd pair it with the *time to work* symbol. When the doorbell rang at 7:45 AM Matisse used to run into the other room to hide, she was afraid of the front door—I was told it was because didn't have the cognitive ability to predict who was on the other side, even though she had been told that Tammy was coming over. Upon hearing Tammy voice she'd eventually relax and emerge to sit and watch some TV.

At 8:00 AM it would be time to start therapy and Matisse would refuse to go with Tammy. An important part of ABA is follow through, so once a verbal directive is given it has to be followed through on. Tammy would say, "Matisse, time to go upstairs". She'd refuse, start to cry and scramble up into my arms. Quite often Tammy would attempt to remove her from my body and Matisse would only kick and scream more. Then, she would go limp, and drop to the floor flailing her arms and legs. Tammy and I would look at each other and try to decide what to do next. Usually I'd offer to carry Matisse up to her room and Tammy would go up the stairs first to get herself ready. I'd pick up Matisse, take her back to the visual schedule, remind her of the activity and the expectations, and then carry her up to her room. As I'd approach her door she'd start to wiggle and fight again, but giving in to Matisse was not an option, because it would only undermine the integrity of the therapists and the program. I'd walk into Matisse's room, sit her in her chair, quickly leave; closing the door behind me and holding the handle so she couldn't get out. I'd hear Tammy trying to get control of the situation by giving Matisse a new directive, "Matisse, sit down", which was

most likely followed by Tammy picking up Matisse, placing her in her chair, verbally praising her, and giving a reinforcement (a small piece of food or a fun little toy). I would hear this happen two or three more times before the crying and the refusing finally ended, and Matisse settle down for her morning three-hour therapy session. Things were this way for months, and every day I'd take a deep breath, wipe away a few tears, and remind myself I was doing the right thing.

JULY 2003

Almost one year later Matisse was a different child. My once echolalic little girl (echolalia is the term used to describe her repeating words and phrases—like an echo) was now asking questions like 'what' and 'who', and no longer fought her therapy sessions. I still remember the first time she asked a 'why' question—I was so excited I started to cry. That summer I had her language and cognitive skills re-assessed, and I remember being nervous. I was so afraid that the results were going to show no improvement, even thought I was certain she was progressing. When the results came back I was shocked. The year before (before she started ABA therapy) she scored below average in every category—somewhere in-between the 3rd and 40th percentile, and she had an IQ of only 70 (below average). However, after only one year of ABA therapy both her receptive and expressive language skills (receptive = what she can understand, expressive = what she can say) were well within the range of normal, and in fact her vocabulary tested about one and a half years higher than her chronological age. The psychologist also did a pre-math assessment on Matisse and she scored over the 90th percentile. The psychologist said she was extremely bright, and that if she hadn't been in such a good program, she wouldn't have advanced so rapidly. The speech and language pathologist said she had never seen gains, like Matisse's, in a child who hadn't had intensive early intervention.

Any doubts I had about ABA therapy, or the intensity of the program

vanished. I knew at that point that all our hard work was paying off and that Matisse was winning the battle against autism. She was moving through the Lovaas curriculum so quickly, mastering new skills and concepts at an amazing pace.

JANUARY 2004

Life with an autistic child is never without it's challenges, and Matisse definitely knew how to make things interesting for us. Six month earlier we were all thrilled at how well she was progressing, and how rapidly she was mastering and generalizing concepts. Generalizing means she is able to learn a skill in one environment, and then replicate it in all environments—i.e. mastering the *occupations* program in the therapy room, and then able to go out into the community and recognized occupations at work. However, by January the discrete trial method of teaching Matisse stopped working. Discrete trial is a short instructional chain, which has three distinct parts: a directive—a behaviour—a response/consequence. The directive might be 'sit down', the behaviour is Matisse sits, and the response for a correct behaviour would be verbal praise, a piece of food, or even a toy. The consequence for an incorrect response might be to try again. For example, during the 'occupations' program the therapist would set out three different occupation picture cards. The therapist would then say, "touch firefighter", Matisse would touch the firefighter, and then be praised and rewarded for the correct response. By January, Matisse was doing these drills to herself. The therapist would set out three cards, and before she could give Matisse a directive (the SD) Matisse would do it herself. Matisse would say, "Matisse, touch truck driver", she would then touch the appropriate card, and then praise herself, "good job, Matisse". At that point we knew it was time to switch to Natural Environment Teaching (NET).

In NET, the program objectives are predetermined, but it is up to each therapist to find new, creative, and age appropriate ways to meet the

objectives. Matisse was very resistant to this change. She preferred the discrete trial format because she knew what to expect, and we saw a dramatic increase in maladaptive behaviours over the next few months. However, during that same time we saw dramatic growth in imaginative and creative free play.

SEPTEMBER 2004

September was a very exciting month for all of us, but especially for Matisse. When she started her ABA program two years before we weren't sure if she would be ready to enter mainstream school with her peers. That summer, Matisse's team worked tirelessly to prepare her for the kindergarten transition. It was the team's goal to academically excel Matisse so the focus of kindergarten would be on socialization. When September rolled around Matisse's behavioural consultant informed me she thought Matisse was ready for kindergarten—again, I think I cried. With every milestone she made, I slowly let my guard down and allowed myself to dream a bit more.

I had spoken to the school a number of times in June to try and make advanced preparations for Matisse on the chance she would start in September. In our school district, children with autism are entitled to half time support. We worried that wouldn't be enough for Matisse but were unable to convince the school she would need more. Before school started we began pre-loading Matisse with images and social stories about her new school. We toured the school, took photos of her classroom, the gym, the library, the principal, her teacher, the secretary, the playground and the bathrooms. We wrote social stories about going to school, and what she could expect to see and do there. The only loose end was we did not know who her SEA (special education teacher assistant) would be—and that concerned us. For the past two years Matisse had attended preschool with a full time aid, one of her lead therapists who has been with us since the beginning, and who Matisse adored. Not only were we concerned that Matisse would strongly

reject her district appointed SEA, but we also worried that this person knew nothing about Matisse, her program, or strategies we used to help her cope. It had been our hope that Matisse and this person could meet before the first day of school so each could become familiar with the other. On the very first day of school we were told that the SEA who had been hired to support Matisse had accepted a posting elsewhere in the district, and that a temporary SEA had been assigned to Matisse. We were very disillusioned and weren't sure what to do next.

Matisse's team had worked very hard to prepare her for this transition, and it was a huge accomplishment for Matisse to even be there, but we worried that without proper support Matisse would either regress or stagnate—two concepts that were completely unacceptable to me. We had come too far to let her slip back away from us. The school assured us that the temporary SEA would be a match, and that they would do what they could to ensure continuity of support should this SEA be replaced. Fortunately, she secured the posting and Matisse didn't have to change again.

Trying to integrate a home based program and school is very difficult. Strategies that we use at home aren't always appropriate or conducive to classroom implementation. Other times, teachers, SEAs and/or resource teachers aren't open to accepting ideas or recommendations. Our first IEP (Individualized Education Plan) took many meetings and went through many drafts, until finally we had to agree to disagree on some issues. While I do think that Matisse's principal, teacher, and SEA have worked really hard to accommodate Matisse, and her home team, it has been difficult (from my perspective) getting the school to realize that our ultimate goal is to make class time easier for everyone. We don't want to replicate our home program at school; we just need to know there are certain supports in place (scaffolding) to ensure Matisse retains the skills she has worked so hard to acquire.

Early on in the program, the prognosis for Matisse was three to four years of solid therapy, and then independent integration into grade one or two (without an aid). I was still working towards, and hoping that goal would be a reality.

MAY 2005

Throughout this school year we have really pushed Matisse socially. At school she is on a token economy system that rewards her for all appropriate interactions with her peers. We monitor her eye contact when she speaks, her eye contact when someone else is speaking, and how well she stays with her peers when playing. For every positive response she is given a token, and at the end of the day she graphs how many tokens she has received that day. She is highly motivated, and reinforced by the number of squares she is able to colour in.

Matisse still continues to work with her therapists two to three hours each day after school. Today we work primarily on socialization and peer interaction. Three to four days per week we have a friend from school come over for a facilitated peer play. During these sessions the focus is on teaching and refining Matisse's social interactions. Matisse still struggles with reciprocal conversations, knowing how to, or when to enter and exit a conversation, and when she is nervous she starts scripting (echoing books or videos) again - it is a nervous response for her. She can also be very rigid and inflexible if she is caught off guard by a big change or something unexpected happens. However, for the most part, if you were to see Matisse on a playground with a group of children, you wouldn't necessarily know she was autistic (or had been autistic as a child).

When Matisse got her first report card in December it confirmed she was fully meeting all the expectations of the kindergarten curriculum. Cognitively she is the same as the children in her class, in fact she actually reads at a grade one/two level. Many of her classmates look to Matisse for guidance when selecting home reading books, and during story time she often reads to her friends. For a child who, at age three, was considered cognitively delayed with an IQ of 70, she has made a remarkable comeback.

Today, her routine is much different then it was a few years ago. Now, she gets up independently, and heads to Mason's room where she chats at him

until he wakes up. She gets dressed on her own, and even adheres to the no skirts or dresses rule without fuss. A new rule has come up in recent months regarding her beautiful, long hair—it has to be tied back to prevent her from stimming on it during circle time. She picks out her own hair decorations and loves it when I do fun and crazy things with it. While Matisse is still a finicky eater, she generally eats without too much fuss, and can even manage to get breakfast for her and Mason while I get myself up and dressed.

Picking Matisse up from school is tons of fun. It is wonderful hearing the other kids chime out, "bye, Matisse", and Matisse responding with, "bye, guys", as we leave the playground. She likes to chat to Mason and I all the way to the car about the different activities she has done that day, and the special craft she has made. Each day in the car she asks, "Mommy, who is coming over today?", referring to her therapists, and when she sees them they are always greeted with hugs. Last week, at the park, one of her therapists overheard her tell a new friend that she was there with her "grown-up friend, Chris."

The last four years have certainly been difficult and overwhelming at times. There were days when I questioned the validity of her program, and my motives for pushing so hard. I have often worried that I haven't allowed her to just be, and accepted her for who she is. However, when I look at Matisse today, and I see her playing, and interacting with other children, I know I have made the right decisions. If I had just left her to be, when she was two or three years old, I firmly believe she would be a withdrawn, rigid, and frightened child today.

Recently someone asked me what my expectations for her future are, and I didn't know what to say. Part of me is still timid about exploring my hopes and dreams for her. However, I have recently realized that it doesn't matter what I want for her, what matters most is what she wants for herself. My goals are to give her the skills and the tools she needs to pursue her dreams. As long as I pour a solid foundation beneath her—security, love, acceptance, belonging, a strong sense of self, and self-esteem, I know she will be able to do anything she wants.

Rett Syndrome

"Yvonne Penner, 30, still lives at home with us. Since leaving the school system at age 21, she has had a day-time companion. Her companion, who is funded through Adult Services, comes to the house Monday through Friday at 9:00 AM. If Yvonne isn't ready to leave (maybe still sleeping because she had a rough night), they get going later. However, for almost three years now, Yvonne usually has her jacket on when her companion arrives! They go for drives, shopping, visiting friends, hiking, or as her companion says, "We do whatever Yvonne wants to do." They arrive back home at 4:00 PM. Yvonne walks very well. Her kyphosis began at 12 years, progressed to 90+ degrees in her mid-teens and has stayed that way. We had agonized over doing surgery but decided against it when the doctor couldn't guarantee that she would walk again. We were also assured that the curvature did not restrict her respiratory system. It's difficult to measure Yvonne's height accurately, but she is near 5-feet. Her weight is fairly steady around 90 pounds. She goes through what I term "her dieting phases" when she eats less and dips down to 85 or even 80 pounds. After a few weeks or months, she has a ferocious appetite and slowly gains her weight back again. It's hard to know why this happens but we no longer worry about it because we've experienced it so often. Yvonne is extremely limited in what she can eat, but generally she eats a lot! Every time Yvonne leaves the house, her food bag goes along! She can't eat anything except what we make for her. If she snitches other food, she'll be awake and crying at night from allergies. When the irritants aren't there, Yvonne laughs joyfully, has a radiant smile, and often hums softly. She truly brightens up everyone's day! She always looks forward to seeing her married sister, brother-in-law, and three nieces and one nephew who range in age from 18 months to 12 years. Still, she prefers to participate

from the sideline. Sometimes she'll leave the busy scene and stretch out on her bed--but always listening! We know because she'll laugh out loudly at very appropriate times . . .

IRMA and PETER PENNER, Fredericton, New Brunswick, Canada.
http://www.rettsyndrome.org/main/i-am-woman.htm

WHAT IS RETT SYNDROME?

Rett Syndrome is classified as an Autism Spectrum Disorder and was identified in a 1966 article written by Dr. Andreas Rett, an Austrian doctor. Rett Syndrome has similar traits to Autism—poor language and communication skills, repetitive hand motions, and decreased social contact, but is *not* Autism. It is a genetic development disorder that can occur in any racial and/or ethnic group and can affect 1 in 10,000 to 15,000 female babies between the age of 6 months and 18 months. After an apparently normal infancy, the baby girl's development regresses and she starts to lose communication skills and fixed use of her hands.

CAUSES

Rett syndrome is caused by mutations in the MeCP2 gene, which is found on the X chromosome. The MeCP2 gene contains instructions for the synthesis of a protein called methyl cytosine binding protein 2 which acts as one of the many biochemical switches that tell other genes when to turn off and stop producing their own unique proteins. Because the MeCP2 gene does not function properly in those with Rett syndrome, insufficient amounts or structurally abnormal forms of the protein are formed.

> *Girls have two X chromosomes, but only one is active in any given cell. This means that in a female with Rett syndrome only about half the cells in the nervous system will use the defective gene.*
>
> (from the National Institute of Neurological Disorders and Stroke-www.ninds.nih.gov/disorders/rett/detail_rett.htm)

Boys with Rett Syndrome seem to die before, or shortly after birth. Those who do survive may not function as well as girls with RS.

STAGES AND SYMPTOMS

The MeCP2 protein weakens the gene's ability to adjust itself during the critical stage of brain development, which is approximately between six and 18 months old. Some cases are more severe than others because if a larger percentage of cells having the X chromosome with the normal MeCP2 gene are turned off, the start of the disorder may occur earlier and the symptoms may be worse. An infant may show less eye contact with reduced interest in her toys and surroundings. She may be described as 'good' baby, calm and placid. There may be a delay in her gross motor skills such as sitting or crawling. Hand wringing may start, as well as a decreased growth in the head circumference, but not enough to draw attention to. Girls may stop responding to their parents and they may not be able to control their feet when they walk.

Stage II could happen between one and four years old and can be rapid or gradual. She may lose spoken language and have increased hand wringing, washing or flicking, clapping or tapping, and may repeatedly move her hands to her mouth. This persists while the child is awake, and disappears when she is asleep. Her breathing is normal during sleep, but when she is awake she may have some breathing irregularities, such as hyperventilation and holding her breath, which may include vacant spells. She may also have

difficulty chewing and swallowing, and sometimes will grind her teeth and drool. Some girls appear autistic-like with loss of social interaction and communication and act generally irritable. She may be thin with a small build, as well as have small hands and feet (this has not been studied rigorously).

Stage III usually happens at around 10 years old, showing an improvement in her behavior. She may become less irritable and not cry as much, show more interest in her surroundings and have less autistic features. She may be more alert and have a greater attention span, and show an improvement in her communication skills. Many girls remain in this stage for most of their lives, without decline in cognition, communication or hand skills. The repetitive hand movements may lessen, and her eye gazing may improve. Curvature of the spine can be a prominent feature (scoliosis) and some stiffness and dystonia (increased muscle tone with abnormal trunk position) is characteristic.

WAYS OF INTERACTING WITH A GIRL WHO HAS RETT SYNDROME

COMMUNICATION: Pictures can be the best communicators for a girl with Rett Syndrome. To help her eyes focus better, place pictures in an up/down pattern rather than side by side. Always assume that the girl understands you, and explain everything before you do it. Computers with switches and touch screens, or intellikeys with yes/no options and computer software that she could interact with would be helpful, as well as interesting. It is important to make sure that activities are age-appropriate, especially if using computer software. Be patient, and let her do one task at a time, waiting for her response. If she dislikes something or isn't interested she could turn away or stiffen her arms/legs. She should be able to understand her own name and some words. She has normal vision and hearing. A girl with Rett Syndrome generally enjoys communicating with familiar people. She may need the use of a speech therapist in the classroom. Some helpful reminders

in the classroom and at home are useful before doing an activity. You can choose signals that she can understand such as words, signs, and pictures.

When trying to get her to act, don't ask her to act. Make comments on the activity or the object. For example, instead of saying "pick up the candy," you could say, "you like candy." Instead of "come sit at the table," try saying "cookies are on the table." Instead of asking her to give a response such as "say hello," just give her a "hello." When she gets started on an activity please don't interrupt her by commenting on what she is doing because she may stop doing what she is working on (just as any child might!).

MUSIC/EXERCISE: Most girls with RS enjoy listening to music or stories on tape. They have an appreciation for colour and enjoy holding objects. They may enjoy listening to singing. Outside activities, such as horseback riding, are good to promote balance. Most girls with RS like cuddling, roughhousing, play, books, television, swinging, riding in a car, bathing and swimming, outdoors, food, photos of familiar people and places, babies and small children (particularly voices).

Why Can Nutrition Be a Challenge?

Girls with Rett Syndrome seem to have a very good appetite, but remain thin. Their body uses energy less efficiently than their peers. Because of a lower dietary intake and lower sleeping metabolic rate this imbalance reduces body growth. Problems chewing and swallowing may be caused by poor tongue mobility. Constipation can also be a problem due to a delayed movement of food through the intestines.

What Research Is Being Done on Rett Syndrome?

Researchers have discovered that the protein MeCP2 binds to the gene BDNF (a central nervous system gene) and silences it, which prevents it from producing protein. When a stimulus excites the neuron cell, MeCP2

breaks away, allowing BDNF to get to work. Doctors may find a way to switch off genes that don't rely on MeCP2. If doctors can slow or stop the progress, they may also be able to reverse its effects. This new information could lead to ways to screen for Rett Syndrome and to detect it before girls feel the majority of the effects. ~

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Rett Syndrome Research Foundation (RSRF): *http://www.rsrf.org* (updated 2004)

A Day in the Life of Susan— a Girl with Rett Syndrome

Susan is a brown-eyed 11 year old girl who tackles her disability with stubborn determination, perseverance, spunk, and a twinkle in her eye. She has Rett Syndrome, a genetic disorder that has similar traits to Autism, such as poor language and communication skills, repetitive hand motions, and decreased social contact. In the past year she has shown an improvement in her communication skills with peers and family and has become more alert and happy in the household and at school.

She lives in Langley with her parents, 45 stuffed animals, her dog Buddy, and a tankful of fish. She loves gummy bears and the Barenaked Ladies and is currently on a modified program in Grade 5 at a Langley elementary school. The following is one day in her life.

MONDAY, MAY 2

7:00 – 9:00 AM

Sleeping in a single water bed keeps Susan's feet warm and toasty. A warm sheet helps to avoid the cold blue feet that plague girls with Rett Syndrome. Susan wears a mouth guard at night to prevent her teeth from wearing down by her constant nightly teeth grinding. With a gentle prodding from her mom, Susan wakes up a little sleepy, just as any 11 year old might.

She has some difficulty shifting her weight while she is walking, as well as some perceptual problems, so she does have a small walker with a seat to rest when needed. Because Susan has beginning stages of scoliosis, a curvature of the spine, the walker keeps her mobile, and helps maintain her overall health.

When she reaches the kitchen for breakfast, she goes to her communication board posted on the wall by the fridge. She points to the oatmeal and

cooked apples—a good choice! Because girls with Rett have poor tongue mobility, there is a delay in the movement of food through the intestines. Susan's body imbalance contributes to her using energy less efficiently than her peers. Constipation can be a problem; for this reason, Susan is on a strict nutrition plan. Eating a balanced diet of healthy foods, and not swaying from the daily routine, helps keep Susan's intestines working smoothly. Chewing and swallowing takes more time than the other family members and eating is sometimes messy. But, it is important for Susan to feed herself and to be allowed the time to do it. Just as you would with any child, giving lots of praise and positive comments helps Susan's self-confidence. She shows her happiness with a laugh and a loud tap on the table with her spoon.

After putting her dishes in the dishwasher, Susan walks to her communication board that is in her bedroom. This board has pictures of different pieces of clothing for her to choose to wear. The pictures are placed up and down, rather than side by side, to improve eye gazing. Because Susan has limited use of her hands, her mom helps her get dressed. This whole morning ritual takes two hours, about an hour and a half longer than her peers.

9:00 AM – noon

After getting dressed, Susan grabs her backpack containing her lunch and her favourite fuchsia velvet rabbit. A *go-talk*, a small portable voice output device that has friendly familiar voices pre-recorded, goes with her wherever she goes. Susan, Buddy and her mom walk to the end of the road and wait for the small school bus provided by the School District to pick Susan up and take her to class.

Most girls with Rett Syndrome need the help of occupational, physical, and speech therapists in the classroom. Susan has occupational therapy two times a week in the classroom, and physical therapy once in the classroom

and twice at home. On Friday nights she goes horseback riding in an indoor riding ring and on Saturday afternoons she is involved in aquatics therapy.

When the bus arrives at school, Joan, Susan's full-time TA, is waiting. Susan presses the go-talk and says "hi, how's it going?" They arrive in the classroom and sit at the computer. Joan turns the computer on and Susan begins her math. While the other children in the class are working on long division, Susan is working on addition and subtraction. She answers the math questions by touching the screen on the computer. This interactive computer software is age appropriate and interesting, as well as colourful. Barenaked Ladies music is played when the correct answer is given. Susan laughs out loud when she gets the answers correct, and the students around her want to know what is so funny. Susan points to the smiley face on the go-talk and it says "I like math."

At recess Susan and her peer buddies sit in a circle on the grass and play a game called hot potato with Susan's stuffed bunny. Someone has brought a small radio and when the music plays they pass the bunny around. Whoever is left holding the bunny when the music stops has to hum or sing the rest of the song that is playing. Susan loves this game because girls with Rett enjoy listening and singing to music, as well as holding objects in their hands. Because this game promotes inclusion Susan feels a sense of belonging.

After recess, Joan works on a goal that is in Susan's IEP. The goal is to eye gaze to match, three times in a row, four colours and four animals placed on the eye gaze frame, to colours and animals on cards held by the teacher.

noon – 3:00 PM

Joan helps Susan get her lunch out and leaves her in the classroom with the other children to eat. Two girls sit with Susan and they talk about boys while eating. After lunch the three girls go outside and walk around the school together and search for colourful rocks on the gravel path. Instead of

saying "pick up the rock," the girls say "you like speckled rocks." They have been taught to say this when trying to get Susan to act. They know not to ask her to act.

When the bell rings to go back inside, because it is such a beautiful day, the girls *slowly* make their way back into the school. Susan all of a sudden stops walking and will not budge off the school grounds. When she is disinterested in something or unhappy she shows resistance by stiffening her arms and legs. The girls take her hand and sing a song while they walk. This makes Susan laugh and they go into the school together.

After lunch, Joan works on a short story with Susan using interactive literature software that scrolls the words across the computer screen. By clicking on the words as they scroll across the screen, Susan is able to compose a funny little story for Language Arts. The TA helps steady her hand and arm. When Susan gets started on an activity Joan doesn't interrupt her by commenting on what she is doing because Susan may stop what she is working on, just as any child might. Joan downloads Susan's story from the computer into the portable school communication device, a digivox. It is similar to the go-talk, but has 48 levels, and can be programmed with 48 messages. Susan uses this device with the help of Joan to present the story in front of her class. After everyone presents their stories Susan claps and laughs.

3:00 – 8:00 PM

When the 3:00 PM bell rings Joan and Susan walk to the bus, and Susan climbs on. Susan's grandma is waiting at the end of her road because her mom had some errands to run. Susan has a small snack, lies down on the couch, turns on the TV and watches her favourite show, *Lizzy Mcguire*. She cuddles her dog, Buddy, who sits beside her on the couch. Most girls with Rett Syndrome like cuddles, books, television, swinging, riding in a car, bathing,

swimming, being outdoors, eating food, and looking at photos of familiar people and places.

When 5:30 PM is near, Susan helps her mom prepare dinner by washing the lettuce and tearing it into pieces. After dinner, the family goes for a drive down to the beach and gets an ice-cream cone. A perfect end to a good day for Susan.

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Tourette's Syndrome

My son, at five and a half, started making awful facial grimacing and jerking movements with his neck and arms. My husband and I thought his brain was shorting out. We were so scared. I wanted to cry. I felt so bad for my son. I just wanted to reach out to him and kiss it all better. Two days later we had an appointment with a pediatric-neurologist. Our son was diagnosed with motor tics. We would have to wait for a diagnoses of Tourette's Syndrome once his symptoms progressed more.

—Signed, *A Mother who does not have TS with a child who does*

WHAT IS TOURETTE'S SYNDROME?

Tourette's Syndrome (TS) is a neurological disorder characterized by repetitive involuntary movements and vocalizations called tics.
—NATIONAL INSTITUTE OF NEUROLOGICAL DISORDER AND STROKE: www.ninds.nih.gov/disorders/tourette/tourette.htm

Tics may include eye blinking, head or shoulder jerking and facial expressions. The most severe and harmful tics are when harm is being done to oneself—punching oneself in the face or biting a lip or cheek. This behavior is extremely rare. Other tics may include mocking someone's words or phrases, swearing or uncontrolled shouting. It is important to note that having TS is not an indication of lower intelligence.

SYMPTOMS

TS symptoms generally appear before the individual is 18. The first symptoms are usually facial tics. Complicated tics may involve jumping, hopping, twisting, turning, snorting, sniffing fidgeting, whistling or making animal noises. Some tics are preceded by an urge or sensation in the affected muscle group, commonly called a premonitory urge. To reduce a sensation or an urge, an individual may find it helpful to do something in a particular way or a specific number of times. Tics decrease when a person is relaxed or absorbed in an activity.

Males are at greater risk of showing TS symptoms than females and are affected about three to four times more often.

CAUSES

At the moment the causes of TS are unknown. According to the National Institute of Neurological Disorders and Stroke, recent research shows that TS may be caused by abnormalities in certain brain regions. It is also said that there is a 50% chance that parents may give TS genes to their children.

DIAGNOSIS

The first symptoms of TS are usually facial tics such as eye blinking or sniffing. In order to be diagnosed a doctor evaluates family history and observes the patient for one year to see if they have both motor and vocal tics.

> *Because tics can wax and wane in severity and can be suppressed, they are often absent during doctor visits, which further complicates making a diagnosis.*
> *—Tourette-syndrome.com/Tourette-syndrome-facts.him#)*

TREATMENT

Treatments range from education and counseling to a variety of medications or no medication at all.

> *Drugs may alleviate some of the symptoms, but currently there is no cure.*
> *—DR. RODNITZKY www.uihealthcare.com/topics/medicaldepartments/psychiatry/tourettes/index.html*

PROGNOSIS

There is no cure for TS; however the condition in many individuals improves as they mature with the frequency of tics decreasing. Tics that may have subsided for months at a time have been known to later return.

People with TS often live on an emotional roller-coaster due to the misunderstanding of their condition by those around them—as well there is a possibility that mood swings, depression, panic attacks and anti-social behaviors can develop due to social isolation.

> *In a vast majority of cases, the most traumatic aspect of the disease is the social stigma it places on its victims*
> *—DR. ROBERT RODNITZKY, Professor of Neurology, University of Iowa*

RELATED PROBLEMS

There is a chance that those with TS will face other problems such as:

- Attention-deficit/hyperactivity disorder
- Difficulties with impulse control
- Obsessive-compulsive disorder
- Learning disabilities
- Sleep disorders

ACADEMIC PROBLEMS

An individual diagnosed with TS may have difficulty organizing their work and may lose supplies needed to complete an activity. It is extremely difficult for a TS student to be involved in a quiet activity because they have the tendency to interrupt or intrude on others and talk excessively. They may also ignore what is being said to them.

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Section 5B

Emotional Disorders

Childhood Anxiety Disorders

Maisy came to the clinic as her parents were concerned about her degree of worry, her physical symptoms due to worry, and her unhappiness at school. Overall, Maisy was described as a child who always anticipated the worst possible outcome. She worried that her father's plane would crash, that her baby brother would fall out of his pram, that she would make a mistake on the weekly spelling test, about what would happen in the future, about passing her driving test (in 10 years time) and the possibility of getting into trouble. Her parents reported that she blamed herself when the whole class got into trouble, and that she felt a need to be perfect at everything. If she made a mistake, she would say things such as "I'm stupid". Her teachers had noticed that her peers felt she was bossy because Maisy was so concerned with keeping to the written and unwritten rules of the school that she would regularly tell them to line up for class ten minutes before the bell, in case they were late. She felt unsafe at night; worried that her mother would leave the front door open and strangers would come into the house while they slept. Maisy worried about her relationships with peers and that others would be mean to her. Maisy's worries were accompanied by numerous physical symptoms. She reported a pounding heart, funny feelings in her throat, butterflies in her stomach, and nausea. Her parents reported that she was often restless, sometimes short tempered with peers, and had difficulty with making decisions. There was rarely a day when Maisy did not express a worry to her parents. Once she began to worry it was difficult for her to stop.

—http://www.psy.mq.edu.au/MUARU/child/stories.htm

WHAT IS AN ANXIETY DISORDER?

A child with an anxiety disorder will often display symptoms such as fear or uneasiness that will prevail for long periods of time. Children with these disorders will often experience worry that will significantly effect and take over their lives. Anxiety disorders can often cause a child to have poor relationships with his or her peers and as a result may cause a child to have low self-esteem. Frequently anxiety disorders can cause children to have repeated absences from school. They often have problems adjusting to new or different situations. There are many different types of anxiety disorders many of which are found in children and adolescents.

WHAT ARE THE MOST COMMON TYPES OF ANXIETY DISORDERS?

GENERALIZED ANXIETY DISORDER. Children with generalized anxiety disorder often have unrealistic worries about everyday activities. This worry takes over their lives on a day to day basis. They may also feel tense or self conscious. It is important for them to have strong reassurance.

SEPARATION ANXIETY DISORDER (SAD) affects one in every twenty-five children. It includes symptoms such as prolonged sadness or depression. Children with this disorder often have trouble leaving their parents for any length of time and are often seen as being clingy or needy of their parents. This can cause sleeping problems for the child as they do not want to be without their parent. Children with separation anxiety disorders often have extreme fears of close family members or friends dying.

PHOBIAS. A child will show an unrealistic fear of certain objects, activities or situations-unrealistic in the sense that the child does not want to go to the park, but they have had no prior experience that would make them want

to avoid this place. A child will try to avoid his fears which in turn can result in a great deal of restriction in their life.

PANIC DISORDERS. This disorder is usually accompanied by what many people refer to as *panic attacks*. A panic attack usually has symptoms such as intense fear, pounding heartbeat, sweating, dizziness and nausea. Children who have experienced panic attacks often live in fear of having another one; because of this they often don't want to go to school or back to the place where their last attack occurred.

OBSESSIVE COMPULSIVE DISORDER (OCD), is experienced by about two in every 100 adolescents. Children and adolescents who have OCD are often trapped in a pattern of repetitive thoughts and behaviors. These patterns are extremely hard to stop. Children with OCD often do their repetitive rituals in privacy; so this disorder often goes undetected.

POST-TRAUMATIC STRESS DISORDER, occurs after a child has experienced a stressful event. The child experiences the event over and over again in memories and flashbacks. Most children with post-traumatic stress disorder also have problems sleeping.

SYMPTOMS AND CAUSES

Anxiety disorders are one of the most common psychiatric disorders found in children and adolescents. Girls are more likely to have an anxiety disorder than boys. Approximately 13 out of every 100 children, between the ages of nine to 17, experience some kind anxiety disorder. Most children will experience more than one disorder. The earlier in life that a child experiences an anxiety disorder the more likely it is that they will have multiple disorders. These disorders have been linked to a number of things such as genetics, brain chemistry, personality and life events. Children are also more likely to have an anxiety disorder if one of their parents has had one. Because

it is hard to indicate why a child might develop an anxiety disorder the symptoms can sometimes be overlooked. A good indicator of whether a child might be suffering from an anxiety disorder is if they are unrealistically worried about one particular place, event or thing. This could be any number of things such as the dark, school or social events. Other indicators that a child may be experiencing an anxiety disorder can include: trouble sleeping, tiredness, nausea, difficulty concentrating, sweating, headaches, muscle tension, irritability, unrealistic view of problems, excessive worry and tension.

TREATMENT

Treatment is individualized for each patient. Cognitive behavioral therapy is often an option for those suffering from anxiety disorders. In this type of therapy children learn how to recognize and change their pattern of thought and behaviors that may lead to feelings that give them anxiety. This type of therapy is designed to try and limit distorted thinking by looking at the child's worries more realistically. Behavior therapy is also an option. This type of therapy is designed to help the child gain control over unwanted behavior and cope with difficult situations usually by controlled exposure to the adverse situation. Relaxation techniques are often used to help children cope more effectively with their anxiety. These techniques usually include breathing and physical exercise. There are many different types of medications available for anxiety disorders. They treat the symptoms of the disorder and allow the child to feel relaxed.

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NYU Child Study center. *http://childparenting.about.com/gi/dynamic/offsite.htm?site=http%3A%2F%2Faboutourkids.med.nyu.edu%2Farticles%2Fabout_anxiety.html* Robin F. Goodman, Ph.D. and Anita Gurian Ph.D. Posted: 10/1/99 Updated: 2/27/01

OTHER HELPFUL ONLINE RESOURCES:

www.mentalhealth.samhsa.gov Child and adolescent mental health. Children's mental health facts.

www.cmha.ca this is the Canadian mental health association's website, a variety of information on mental health and anxiety disorders can be found on this site.

Copyright 2000 Aboriginal youth network
My life: it's cool to talk about it (focus on youth mental health)
Youth and mental illness: Early intervention

Research

www.canadian-health-network.ca A large inventory of information on both physical and mental health including anxiety disorders. Anxiety disorders. Treatment and support information.

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A Day in the Life of Maria—a Girl with Anxiety

My name is Maria and I'm 11 years old. I have an anxiety disorder and because of it I worry all the time. I worry about getting to school on time, getting my homework done, will I get sick, or even worse, will someone I know get sick. I don't just worry about myself. I really worry about the people around me as well. I worry about my friends being late for school or missing the bus, I worry about my teacher being sick and not being able to make it to school, and I worry a lot about my parents. Because of all this worry my parent took me to see a doctor; so now we have a name for why I'm always so upset; *generalized anxiety disorder and panic disorder*. The doctor said that most people with an anxiety disorder have more than one, he also told me that girls are more likely to have one than boys. The doctor gave me medication that I take to make my worry go away. I take these pills and I go to another kind of doctor who teaches me relaxation techniques that I can use when I think I'm going to worry or panic. Both doctors tell me that most people with anxiety disorders usually go to different kinds of doctors for help, and have to go to more than one doctor just like me. It also made me feel better when I found out that I'm not the only one that this has happened to. About 13 out of every 100 children or teenagers have a type of anxiety disorder.

Along with all the worrying I get other symptoms too. Sometimes my symptoms can be really bad, like the other day in school we started a new class with a new teacher. I don't know why, but I didn't want to go and the teachers told me I had to, so my heart started racing a hundred miles an hour, I felt dizzy and like I was going to throw up and I couldn't stop shaking

and crying. All I knew was that I didn't want to go at all. I get symptoms like this fairly often, but usually only when I don't really know what is going to happen next. My mom and dad and I talked about what happened with my doctor, and I thought maybe I was going crazy. The doctor told us that many people with anxiety disorders have difficulty adjusting to new or different situations; he also told me that all the symptoms I was feeling, like the pounding heart and dizziness was actually what most people call a *panic attack*. This made me worry more, because I didn't want to have another panic attack, it was really really scary. Just thinking about having another attack was making my heart race. That's when the doctor told us that most people with a panic disorder worry all the time about having another attack. This actually calmed me down a bit. I guess I'm not so strange after all.

It wasn't that easy figuring out what was wrong with me—in fact it was really hard. I had to go through all sorts of tests. The doctors were not sure if I had something like mono or asthma or even worse if I had a heart condition. This really scared me and made me feel afraid of going to the doctors. I tried to get out of going to the doctors because of how scared I was. I didn't want something bad to be happening to me. What if it was a heart problem and I had to have surgery? The thought of this made it really hard for me to sleep at night; I often found myself lying awake all night thinking about all the horrible things I thought were wrong with me. When I found out that I had an anxiety disorder I would like to say that I was relieved, but I wasn't. I didn't know what anxiety was. I didn't know how I got it or how I was going to get rid of it. I now know that they don't know why people get anxiety disorders. I know that I'm not going to just get rid of it, it's something I'm going to have to work through. One doctor asked my parents if they had ever felt like me. Sometimes kids that have this problem have parents that used to have the same thing. I found out that my mom used to have problems being depressed. I'm happy to know that my mom no longer feels depressed. It is also nice to have her to talk to about how I'm feeling. I know she has had some of the same problems that I have. Some researchers think that anxiety

disorders might be caused by problems in the environment or even different chemicals in your brain. Weird, huh?

Now that I understand why I feel the way I do, I don't feel so bad. I understand that there really isn't any reason for me to feel so afraid of certain things. Although my worries don't come around as often as they used to, I still sometimes get these feelings my doctor calls *fight or flight*. These are the feelings that I get when something happens and I don't know what to do. I either get really angry or just want to run away and hide. My doctors are helping me deal with these feelings. I'm lucky because some of my teachers and an EA got together to help make some strategies for me at school. They gave me a day planner. Everyday my teacher writes the events of the day on the board and I copy them into my planner. This helps me because I really like to know what is going to happen next. They also gave me a stress meter—this is a meter I use to show how I am feeling. My teachers and doctors are helping me realize what I am feeling and are helping me deal with those feelings. I'm glad that we now understand what is going on. I'm not as afraid any more because I know that my symptoms, like my racing heart, don't mean that I have a heart condition or that I'm going to need surgery. I am no longer afraid to go to the doctors because I now know that they can help me.

I hope that other kids that have anxiety disorders know that they are not alone; there are a lot of us out there. I hope that they are as lucky as I am and get the help they need to feel better and to understand how to deal with their symptoms and feelings. I'm really glad that I have control back over my life. I can get back to being the kid that I want to be. ~

Childhood Depression

There is no clear-cut reason as to what causes depression. The medical community knows very little about the brain.

Depression, can be triggered by certain events. Among these triggers are: a family history of mental illness or suicide, abuse (physical, emotional, or sexual) chronic illness, or a loss of a parent at an early age due to death, divorce, or abandonment. (www.wingofmadness.com).

When children suffer from depression at a young age, where none of the typical triggers have occurred yet, their depression is believed to be a chemical imbalance and not psychological. Each case of depression is very different and needs to be looked at carefully.

SYMPTOMS

PHYSICAL: headaches, stomach, joint or back aches, lack of energy, problems sleeping, weight or appetite change

BEHAVIOR: restless, irritable, withdrawn, cuts class, drops out of hobbies, drinks, drug use, finds it difficult to get along with others

FEELINGS OF: sadness, emptiness, guilt, worthlessness, hopelessness, lack of joy in everyday pleasures

TREATMENT

If the child is in danger of harming themselves then hospitalization is necessary.

If a child has been diagnosed with either major depression or dysthymia (milder case) then psychotherapy and or medication is an option.

If the depression is psychological, medication won't be the answer. It may relieve the depression for a time but the underlying cause will not be addressed. Therapy can help a child to deal with his or her past in a healthy manner and learn ways to cope with the very difficult process of growing up.

MEDICATIONS AND TREATMENTS

Antidepressants: such as effexor, paxil, and older tricyclic antidepressants.

These drugs are usually not recommended for children under the age of 18. In recent studies paxil is said to increase suicidal thinking and suicidal attempts in children. Most professionals recommend therapy as the first line of defense.

Early diagnosis and treatment are essential for those with depression. Youth who exhibit symptoms of depression should be referred to and further evaluated by a mental health professional who specializes in children and teenagers.

Diagnostic evaluation may include psychological testing, laboratory tests and consultations with other medical specialists such as a child psychiatrist. A comprehensive treatment plan may include psychotherapy, on-going evaluations, monitoring, and psychiatric medication. Optimally the treatment plan is developed with the caregiver. Whenever possible the youth should be involved in their healthcare decisions. (*www.nami.org/Content/ContentGroups/Helpline1/Fact_About_Childhood_Depression.htm*) ~

CHILDHOOD DEPRESSION

Most people long to be back in the care free times of their childhood. We often forget that growing up wasn't always easy. Children are powerless and have no real control over their own lives; so when a family situation is rough

and unhealthy, the child has no escape route. This often can lead to depression. Things like peer acceptance and grades can also be stressful and upsetting for children.

Clinical depression is long lasting, pervasive and life threatening. It's much more than a few highs and lows. It must be treated with psychotherapy, medication, or both.

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Wings of Madness. *www.wingofmadness.com*

ADDITIONAL RESOURCES

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Eating Disorders

By the end of my junior year of high school I weighed 104 pounds. I had lost 34 pounds. The effects of the weight loss had changed my body. The funny thing is I lost the weight to look better, but physically I felt so much worse. I was always tired and irritable. I would come to school annoyed with everything. I was 5' 5" and 104 pounds and as crazy as it sounds I did not think I had a serious problem . . . or at least I did not admit it to myself. I never told anyone what was going on. I guess, I thought that if I admitted that I had a problem then the whole thing would become real.

One day during a track meet reality set in. I was scheduled to run four races, but only completed one. I ran the 200-metre, one of my best events, and finished in 5th place. Next was the 400-metre. This race is hard enough when I was in good condition, but because I had not eaten anything substantial in weeks I collapsed on the track. I completely blacked out. I could not even stand up by myself. That night I went home and cried. That one event scared me to death.

From that day on, with the help of my family, I was slowly able to come to terms with my problem. It was a slow recovery. I cannot say that I never think about my weight or how I look, but something has changed. I appreciate and care for my body. No one is perfect. —*Caitlin*

— *http://www.eating.ucdavis.edu/speaking/told/anorexia/index.html*

TYPES OF EATING DISORDERS

TYPES: anorexia nervosa, bulimia nervosa, binge eating, and compulsive eating

ANOREXIA NERVOSA is characterized by a significant weight loss resulting from excessive dieting. People who suffer with anorexia consider themselves to be fat, no matter what their actual weight is.

BULIMIA is characterized by a cycle of binge eating followed by purging to try and free the body of unwanted calories. Vomiting, laxative abuse, excessive exercise, fasting, use of diuretics, diet pills and enemas are all forms of purging.

BINGE EATING and COMPULSIVE OVEREATING are very similar—both are characterized by eating large quantities of food resulting in weight gain. The difference between the two is that binge eating is done for a short period of time until the individual is painfully full. These two eating disorders are similar to bulimia but the individual does not use any form of purging after the binge. Children will often feel out of control while they eat. Feelings of guilt or shame follow after. It is very common for someone to suffer with more than one eating disorder. Eating behaviors are only symptoms, of an underlying problem.

SIGNS AND SYMPTOMS OF AN EATING DISORDER

ANOREXIA: noticeable weight loss, depression, excessive exercise, obsession with food, excuses for not eating, and evidence of vomiting, laxative abuse, diet pills or diuretics

BULIMIA: binge and/or secretive eating, bathroom visits after eating, fasting, mood swings, and avoidance of restaurants

BINGE EATING: weight gain, feeling out of control, over eating, fluctuations in weight, hiding food, and trying diet after diet

COMPULSIVE OVEREATING: eating very little in public, while maintaining

a high weight, feeling tormented by eating habits, withdrawing from activities because of embarrassment about weight, and binge eating

The most common sign (and drive) of all eating disorders is depression. Recovery takes time, hard work, and proper treatment. Anyone can fully recover from an eating disorder.

CAUSES AND WHO IS MOST AT RISK

Today more children under the age of twelve are developing eating disorders. Children who are raised in a dysfunctional family are at a higher risk. They often use eating as a way to gain control when they can not control their lives. A child with an eating disorder my also be using it as a way to express their emotions. They may have feelings of anger, sadness, loneliness, abandonment, fear and pain. Children who have parents who are preoccupied with appearance and weight, and even children who grow up in a good family environment, can develop an eating disorder. Society and the media are sending messages to everyone about the look of perfection. Unfortunately, this can cause children to believe that the world will only accept you if you look a certain way. A self-evaluation quiz is available at *www.anad.org* (located in Eating Disorder Info & Resources)

HOW CAN YOU HELP?

- Realize that everyone can be helped.
- Know that recovery is not easy, it takes time. There are organizations to help the person with the disorder.
- Remember to be patient, gentle, and non-judgmental. Be persistent about encouraging a person who has an eating disorder to seek professional help.
- Do not tell others what to do, but be encouraging and don't get too emotional or critical.

It is important to know when to take immediate action! Although people who suffer from eating disorders need to recover on their own, there are times when their state of health is put in danger and immediate medical attention is necessary. If you feel that a person needs immediate medical attention phone 911.

Most children who have eating disorders go through several stages of awareness and acceptance of their condition. At each stage they may respond differently to the various approaches to getting treatment. For information about what's most likely to work at each individual stage please refer to: *The Unofficial Guide to Managing Eating Disorders,* Sara Dulaney Gilbert & Mary C. Commerford, Ph.D.

TREATMENT

Treatment options can range from basic educational interventions designed to teach nutritional and symptom management techniques (outpatient) to long-term residential treatment. Patients go through an initial assessment to review their history, current symptoms, physical and mental state. There are many different types of outpatient psychotherapies which have proved effective in patients. Psychiatric medications have demonstrated a role in the treatment of patients. Nutritional Counseling can be an effective source of support and information for patients who are trying to change their eating behavior. Day hospital treatment programs are available for patients who are able to live at home and still go to school or work. These programs generally run from three to eight hours a day and include structured eating sessions, cognitive behavioral therapy, body image therapies, family therapy, and numerous other interventions.

Medical treatment resources in the Lower Mainland area:

- St. Paul's Hospital, Eating Disorders Department, *www.stpaulseatingdisorders.ca*
- Vancouver Health Authority, *www.disorderedeating.ca/map/avanhr/html*

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Local Support Centers: St.Paul's Hospital

Eating Disorders department, www.stpaulseatingdisorders.ca/

Vancouver Health Authority, www.disorderedeating.ca/map/avanhr.html

Obsessive-Compulsive Disorder

Five-year-old Alex can't go to sleep until he kisses his mother five times on each cheek after she closes his closet in a certain way. He has no other fixed behaviours.

Jesse, 10 years old, cleans his teeth so frequently that he uses a box of toothpicks each week and his gums bleed profusely. Each day he uses a half box of Q-tips to clean his ears and a roll of toilet paper when he goes to the toilet. When he does his homework, Jesse can spend an hour on the same page, erasing and rewriting words because he's sure he didn't get them right.

Ashley, l6, reports that each time she leaves a classroom, passes the principal's office or leaves school, she has to imagine the number 12 on a clock and say the words *good luck* to herself. She reports that she can't stop thinking about the words good luck. If she tries to stop herself from thinking about these words, she becomes very anxious and worries that she'll have a heart attack. In the classroom, she is often frozen in her seat, unable to respond. She worries that any decision she makes will result in something dreadful happening to her parents. Before going to sleep, she closes the bedroom door four times, turns the lights on and off four times and looks out the window and under her bed twelve times.

—ROBIN F. GOODMAN, PH.D. and ANITA GURIAN, PH.D. (2001)

AN OVERVIEW

Children suffering from obsessive compulsive disorder (OCD) tend to be

bright, articulate, high achieving, intelligent, creative, and sensitive. They are not unstable, schizophrenic or psychotic. Some famous personalities who are affected by OCD include Marc Summers, Roseanne Barr, Woody Allen, and Billy Bob Thornton. In Marc Summers book, *Everything in Its Place,* he writes, "One of the greatest side benefits of waging war against OCD and winning is an awakened empathy for others." He also stresses how important motivation is in overcoming this disorder.

WHAT DOES OCD LOOK LIKE?

One in 40 individuals are affected by OCD; although it is common it causes a lot of shame among those who are affected. As a result of this shame and embarrassment people will try to hide this disorder from others making it difficult to diagnose without psychiatric intervention. Obsessions are persistent and repetitious, unwanted and intrusive. Inappropriate thoughts, impulses or images may include any of the following: thoughts of harm coming to oneself or others, fear of contamination by germs, sexual impulses/thoughts, religious doubts, moral scrupulosity, fear of embarrassment, fear of loss, danger, excessive superstitions, fear of being imperfect, and fear of losing control.

As a child attempts to stop these thoughts then may perform what are known as compulsions—repetitive actions: daily rituals, frequent washing, checking the environment for signs of danger, persistently asking for reassurance, counting and/or arranging, praying, confessing, touching, protecting behaviours, grooming, re-adjusting, food-based rituals, saving or 'hoarding' useless items, and excessive self monitoring behaviours. Children may also attempt to avoid school if this environment triggers these symptoms. At school, children may take more time completing activities or following directions. They are sometimes negatively labelled as *lazy procrastinators* when in fact they are working hard to avoid obsessing.

CAUSES

Obsessive compulsive disorder is considered to have both genetic and neurobiological origins that may or may not be triggered by seizures or illness such as strep throat. Technology shows that extra activity is occurring in parts of the brain that are in charge of unconscious movement, impulsiveness, fear and rage that requires more mental energy than usual. Some children may have trouble screening out irrelevant thoughts and/or have difficulty processing information.

OCD SPECTRUM DISORDERS

Children affected by OCD are also more likely to be affected by Tourette's Syndrome or other 'tic' disorders. Trichotillomania which is a hair pulling disorder, body dysmorphic disorder which occurs when people obsess about what they believe to be defects in appearance, extreme nail biting and skin picking are considered to be within this spectrum but are seen as impulsive rather than obsessive-compulsive behaviours.

THERAPIES

Cognitive behavioural therapy (CBT) is considered to be the most effective therapy for treating people who are affected by OCD. It involves children deliberately exposing themselves to the thoughts and/or images that cause them to engage in compulsive behaviours in order to help desensitize them and to minimize thought occurrences. Also involved in CBT is the deliberate choice to increase the time between the occurrence of the obsession and the compulsive behaviour(s) working towards ending these behaviours altogether. When the child is becoming comfortable with the exposure and response part of this therapy the cognitive part should begin. This involves

changing thought patterns. This is viewed as therapy maintenance and prevention as well.

Obsessive compulsive disorder is associated with low levels of serotonin. Medications to treat children affected by OCD are known as serotonin reuptake inhibitors or SRI's. Zoloft, paxil, luvox, and prozac may help to restore balance and normalize the hyperactive regions of the brain. These medications are also used to treat depression and anxiety that often accompany OCD. They are viewed as a short-term therapy that may help to achieve the effects of cognitive behavioural therapy sooner.

CONSIDERATIONS

Children need to be motivated for therapy to be successful. This is achieved as informed, supportive family members and teachers offer encouragement, praise, acceptance and compassion and monitor and record progress. OCD does not just affect the child but family members as well; therefore therapy for the entire family is very beneficial. Therapy can help family members to disentangle themselves from the rituals involved in OCD and also help them to balance expectations and avoid perfectionism. For educators, modifications, adaptations and the minimization of distractions may help to increase student success.

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Childhood Schizophrenia

Emily Huff was a fourth-grader when she met Zephyr, a large, powerful wizard who wore a flowing cape and carried a staff topped with a glassy blue orb. Two years later, she began seeing visions in the bathroom mirror at Kimball School: words and red letters, a hand reaching out of the glass. Some days, a gray-skinned boy she called Orion would appear to her on the playground, asking her for help, then vanishing. Other times, Emily was convinced aliens were trying to capture her, that she was only safe near heat. During a sixth-grade math class, she held her hand against a baseboard heater, charring her skin in order to escape a fear no one else understood.

There is no way for most people to comprehend what it's like to have schizophrenia, says Emily, who is now 19. She wishes there was a magic helmet for the rest of us, a device that would transmit the unreal voices, the hallucinations, the terrifying thoughts that invade the schizophrenic mind without warning. After an hour of wearing that burden, people might know the truth.

—PROULX (2004) *www.concordmonitor.com*

WHAT IS CHILDHOOD SCHIZOPHRENIA?

Schizophrenia is a serious mental illness that affects the brain. It causes major problems with thinking, emotions, behaviour and communication. It is an uncommon psychiatric illness in children. It usually appears in individuals in their late teens to early twenties. Children seem to have more severe cases than adults.

Schizophrenia is one of the most serious mental illnesses in Canada. Globally, nearly 3% of the total human disease burden is attributed to schizophrenia. There are five classifications of this disease: *catatonic*, *disorganized*, *paranoid*, *residual* and *schizoaffective* disorder. All are classified by the type of symptoms experienced. Public misunderstanding and fear contribute to the serious stigma linked with it. Mortality associated with schizophrenia is one of its most distressing consequences. A high percentage of individuals with this disease will abuse substances during their lifetime.

CAUSES

The exact cause is unknown, but, a combination of genetic and environmental factors is considered to be responsible for the development of this functional abnormality. These factors appear to affect the development of the brain at critical stages during gestation and after birth. Immediate family members are 10 times more likely than the general population to develop it. Potential environmental contributions to the development are: prenatal or perinatal trauma, and season and place of birth. Studies have established a link between severe social disadvantages and schizophrenia.

TREATMENT

Schizophrenia can be treated effectively with a combination of antipsychotic medications. This illness can be controlled but not cured. Through education, primary care services, hospital-based services and community support, the affects of this illness can be improved. Most children affected by schizophrenia are treated in their community; although, sometimes hospitalization is necessary to stabilize symptoms. Responsibility for primary care falls on family members, which can be costly. With effective treatment, further symptoms can be prevented and the chance to lead a full and productive life increases.

MAJOR SYMPTOMS

- Delusions
- Hallucinations (auditory, sight, touch)
- Confused, bizarre thinking behaviour
- Depression
- Lack of motivation/energy

Disorganized speech
Disorganized / Catatonic
Social withdrawal
Paranoia

Many other symptoms are also associated with schizophrenia including: changes in eating and sleeping patterns, headaches, strange head sensations, and unusual ways of showing emotion. With schizophrenia, these symptoms gradually emerge in children and quite often changes in emotional relationships with family and friends occur. Schizophrenia has a profound effect on the child's ability to function effectively in all aspects of life for example: self care, relationships, school, community and social life. Ongoing social problems occur throughout life. Early on the affected child may lose the ability to relax, concentrate or sleep. Quite often performance at school and any work they might be involved in suffers.

Along with these schizophrenic symptoms the affected child often has one or more of the following: seizures, learning disabilities, mild mental retardation, neurological symptoms, hyperactivity and other behaviour problems, which will remain with them into adulthood.

WHO DOES IT AFFECT?

Childhood schizophrenia affects children younger than 15 years of age. Children who have two parents with schizophrenia have a high chance of developing it. Approximately 13% of individuals, whose mother's have it, will develop it. Males usually develop this disease earlier with a 2:1 ratio male to female. Once this illness develops, it affects both sexes equally. Before the age of five, childhood schizophrenia is exceedingly rare. Between the ages of five to 15, chances increase.

Typically, schizophrenia occurs in late teens to mid thirties. It is estimated that it affects 1% of the Canadian population and 0.2 – 2% worldwide. One of the most heart-wrenching facts about schizophrenia is that about half of the individuals that have it will attempt suicide and about 10% will succeed.

DIAGNOSIS

If there is any indication that a child might have schizophrenia, the pediatrician or family doctor needs to be contacted. Other professionals that can aid in this area are the child's teacher, a child psychologist, a psychiatrist and a social worker.

The child must continuously show *two or more* major symptoms for *at least a six month period*. Any symptoms or indications of schizophrenia must be severe enough to cause dysfunction in one or more areas of functioning, such as, social life and school.

MRI studies have shown that children with childhood—onset schizophrenia continue to have progressive brain changes related to the disease during adolescence. It is important to know that there are no lab tests to absolutely confirm a diagnosis; decisions are mainly based on clinical observation; so getting a second opinion from another professional is highly recommended. ~

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A Day in the Life of Taylor— A Boy with Schizophrenia

Taylor is a boy in grade seven who lives with his mom, dad and two brothers. He is the eldest child and very proud to be. Taylor lives in a quiet suburban neighbourhood with lots of children his age. He loves sports and playing video games. He has always been a very active child and has been diagnosed with borderline ADHD (attention deficit hyperactive disorder). A couple of years ago, Taylor started to hear voices, not voices from people but from beings in outer space. At first, it seemed like a game to his parents, since he had always had a great imagination. When Taylor became afraid to go to school, because of these hallucinations, his parents started to worry. He became very withdrawn from his friends and family. He quit the soccer team he was on because he said that everyone was out to get him and no one understood him. His younger brothers became afraid of him; he would talk to himself a lot, sometimes argue and yell at no one. Sometimes Taylor would stay up all night waiting for the *aliens* to come. His parents talked to his teacher who told them he had been seeing *aliens* in the class too. It became very hard for him to concentrate and the students distanced themselves from him. A very active, popular child before, now became seen as the *weird kid* who talked to himself.

Taylor's parents took him to their family doctor who referred him to a child psychologist. After more than a year of continuous symptoms and many tests and scans later, Taylor was diagnosed with childhood schizophrenia. Because childhood schizophrenia is so rare, the doctor was very hesitant to make this diagnosis, especially before adolescence. Doctors are still unsure of how Taylor became ill because no one in his family has any

history of it, and when MRI and EEG scans were taken nothing came up extraordinary. Yet, Taylor is very extraordinary.

It is very hard for people to identify with a mental illness because there is no physical aspect to it. That was the hardest thing for Taylor's friends and family to realize, his appearance never changed just the things he said and thought. Since being diagnosed, Taylor has been on a number of anti-psychotic medications. These drugs have been able to control his symptoms but not cure them. His medication has helped school and family life a lot. He does not get so many hallucinations and delusions, and he has started to interact with people more. Taylor's teachers and teacher assistants have been better equipped to handle his behaviour. Taylor's teachers have talked to his classmates about his illness and have explained and answered any questions they might have. The dialogue with the students has created a better understanding of what Taylor is going through, and his classmates are better able to help him rather than avoid him and call him names.

In the morning, before school, Taylor takes a combination of anti-psychotic medications. Again at lunch, on his own, Taylor goes down to the medical room to take his second dose of medication. In the evening around supper time, Taylor takes his last set of medication for the day. This dosage amount has been working for him for six months now; the first amount did not work well enough for him, so his dosage amount was raised.

When Taylor comes to school in the morning, he takes off his coat, puts his backpack away and sits at his desk. While waiting for the bell to ring, he will get out a book about any kind of sport and sit reading or drawing while the other students talk and interact with each other. On bad days, Taylor will stay in the cloak room and whisper about aliens and outer space until his teacher, Mr. Smith, or his teacher assistant, Lucy, will come and get him to sit at his desk. On these days it is a challenge for Lucy and Mr. Smith to coax him out of the cloakroom because his hallucinations and delusions are very real to him and he gets scared. Having the other students know about his illness helps, because they are sometimes able to help talk him through

his hallucinations or delusions more effectively than Mr. Smith or Lucy. Bad days do not happen too often, but when they do, it takes time for Taylor to calm down. Sometimes, he gets too disruptive on these days and there is no calming him down. When this happens he is sent to calm down in the medical room and Lucy comes with him, if that does not work he is sent home.

Today Taylor came to school in a good mood. He came into the class, went to the cloak room and put away his things. He took out his favourite book about baseball and began to read. The bell rang and the rest of the students came in along with Lucy and Mr. Smith. Math was up first; lucky for Taylor it is his favourite subject. About fifteen minutes into the lesson, the fire alarm went off. Mr. Smith and Lucy told everyone to stand up quickly and get in line at the door. Taylor could not move. He put his hands to his ears and started to yell. The aliens had come back and they were coming to take him away. Mr. Smith took the class outside while Lucy tried to calm Taylor down so she could bring him out. He kept saying that the aliens were there and he needed to go somewhere safe so he did not get taken. Lucy, having dealt with situations like this before, took hold of Taylor's hands and looked into his eyes. She said that he was going to be okay and that she would not let anyone take him. Lucy told Taylor that the bell sounding off was the fire alarm and that they were having a fire drill. Taylor asked her how she knew the aliens would not take him.

"Well", she said, "because I have a secret cloak that makes you become invisible to alien detection." She went and got her coat out of the cloak room and put it around Taylor. "There, now the aliens will not see you. But we have to go outside right now because we are having a fire drill." Very reluctantly, Taylor followed Lucy outside with her coat wrapped around him. They joined the rest of the class and checked in with Mr. Smith so he would know that they were outside. For the rest of the day Taylor was very skittish and had many hallucinations of aliens and beings from other planets coming to take him. Mr. Smith and Lucy had a rough time trying to get him to concentrate on his work. They brainstormed some ways to incorporate his

delusions and hallucinations in order to try to get him to do some work; for example, in art he was asked to draw what he was seeing, in reading he wrote a story about the aliens and beings that he thought were coming for him, in spelling he was given spelling words that related to outer space and protecting oneself. Lucy remained close by him the whole day to reassure him that he was okay. She did not want to break his trust or have Taylor become scared again.

Taylor is a very bright boy that enjoys learning, but it is a constant challenge when working with him because he gets very scared and acts out according to what is happening in his mind. He does not joke around or pretend; he believes what he sees, hears and feels. A lot of the time there is no warning to what he is going to do or say. Lucy, Mr. Smith or one of the other students will stay with him and try to talk him out of his delusions and thought disorders, and most of the time it works.

If the rest of us could see what goes on in Taylor's mind we might have some small idea of what he goes through everyday.

Section
5c

Intellectual Differences

Down Syndrome

Down Syndrome is a genetic condition characterized by an extra 21st chromosome. It is the most frequently occurring chromosomal disorder occurring in 1 out of every 800 to 1000 live births.

Children with Down Syndrome have some degree of intellectual and physical developmental delay as well as some similar physical features. Intellectual delay can range from mild to severe.

Down Syndrome is named after an English physician. In 1866 he published an article in which he described a group of children with similar physical features that were different from other children with mental retardation.

In 1959 a French geneticist named Jerome Lejeune discovered that Down Syndrome is caused by a problem with the number of chromosomes that a person has.

PHYSICAL CHARACTERISTICS

Down Syndrome is usually diagnosed at birth by physical characteristics. The diagnosis is confirmed by a karyotype or chromosome analysis, which is done by examining blood or tissue cells. There are many physical characteristics that are commonly seen in children with Down Syndrome. Some children have only a few of these characteristics, while others have many.

Among the most common characteristics are: a flatter facial profile, a somewhat depressed nasal bridge and a small nose, an upward slant to the eyes, small skin folds on the inner corner of the eyes, slightly smaller ears, small hands and feet, short arms and legs, small mouth, a single deep crease across the center of their palm, decreased muscle tone, loose ligaments, excessive space between large and second toe and an enlargement of the tongue.

TYPES

Down Syndrome is a genetic defect caused by abnormal cell division in the egg, sperm, or fertilized egg. It is not known why this abnormal cell division occurs.

There are three types of Down Syndrome all caused by chromosome abnormalities: *trisomy 21, translocation* and *mosaicism*.

Trisomy 21 occurs in about 95% of all people with Down Syndrome. An abnormal cell division causes them to have an extra 21st chromosome in every cell in their body. Most often the abnormal cell division occurs in the egg, either before or at conception.

Translocation occurs in 3% to 4% of all people with Down Syndrome. During cell division, the extra 21st chromosome breaks off and attaches itself to another chromosome either before or at conception.

Mosaicism occurs in 1% to 2% of all people with Down Syndrome. There is an abnormal cell division after conception, resulting in some cells having 46 chromosomes and some having 47.

HEALTH ISSUES

- About 40–45 % of the children have congenital heart defects. Many of these children will require cardiac surgery.
- A child with Down Syndrome has about a 60% chance of having problems with their eyes.
- Hearing deficits occur in 60–80% of the children.
- A child with Down Syndrome also has a greater risk of having digestive system problems, thyroid disease, skeletal problems and sleep apnea.
- An adult with Down Syndrome has an increased risk for developing Alzheimer's disease.

LIFE EXPECTANCY

The life expectancy for a child with Down Syndrome has increased dramatically. In 1929 the average life span for a child with Down Syndrome was nine years. Today most of the health problems associated with Down Syndrome can be treated and the life expectancy has increased to 55 years.

THERAPY AND TRAINING

- SPEECH & LANGUAGE THERAPY to help the child express themselves
- PHYSIOTHERAPY to enhance development of early motor skills, such as sitting, standing, or walking
- OCCUPATIONAL THERAPY to improve functional skills in small motor skill areas, such as eating or handling objects and fine motor skills such as buttoning and unbuttoning clothes
- MUSIC THERAPY can help make changes in learning or behaviour patterns. Rhythm, rhyme and music are powerful tools to support memory.
- NUTRITIONAL COUNSELLING can help a children with Down Syndrome maintain a healthy weight
- VOCATIONAL TRAINING can help persons with Down Syndrome be independent and reach their full potential

TEACHING A STUDENT WITH DOWN SYNDROME

- Most children with Down Syndrome can learn to read.
- Children with Down Syndrome frequently have strengths in visual learning and difficulty with auditory learning.
- Speech is the most difficult form of communication for a child with Down Syndrome to learn.
- Children with Down Syndrome often have poor auditory short-term

memory, which may be another reason they have difficulty learning grammar.
- The reading ability of children with Down Syndrome is one of their better cognitive skills.
- A student with Down Syndrome will learn better by being able to see and touch learning materials. Visual learners are able to see things before they can talk or write about them.

The strategies below have been taken from the *Teaching Students with Down Syndrome* Information series by Carol Johnson.

- Use verbal cues: songs, rhymes, mantras, key words, and repetitive phrases
- Use visual supports: visual schedules, photos, organizational charts, mnemonics, personal spellers, colour codes, manipulatives, subject tabs, diagrams
- Chunk concepts and materials together
- Provide activities that relate to the ability and learning style of the student (such as reducing the level, length and or the difficulty of the task)
- Ask questions that the student understands, using fewer words and speaking slowly
- Use concrete materials based on real life experiences as *bridges* to more abstract learning activities
- When testing for learning, vary the content, assessment method and time
- Establish routines and teach the student how to follow them; allow practice time and review often
- Break tasks into small steps and define each step

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Down Syndrome Research Foundation and Resource Centre
Address: 1409 Sperling Avenue Burnaby, BC V5B 4J8
Phone: 1-888-464-DSRF 1-888-464-3773
(604) 444-3773 Fax: (604) 431-9248
Email: info@dsrf.org, www.dsrf.org

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Section
5 D

Muscular-Skeletal Conditions

Cerebral Palsy

The best advice parents of children with cerebral palsy could receive is to treat your child like a person. This may sound trite, but it is too easy to focus on the disabling condition and not the whole person. I am a person with cerebral palsy but I am also a person who likes baseball. I am a person who likes to dance. I am a person who wants to be a parent. And I am a person.

—TOM RITTER Foreword in *Children with Cerebral Palsy: A Parent's Guide* (2nd Edition 1998)

WHAT IS CEREBRAL PALSY?

Cerebral Palsy (CP) is a broad term used to describe a variety of disorders that can affect an individual's ability to control movement, posture and balance. These disorders can result in physical coordination or involuntary movement problems of the arms, legs, neck and face.

CP affects the brain's ability to control the muscles. The muscles, or nerves connecting the muscles to the spinal cord, are not directly damaged; instead, the part of the brain that is injured interferes with messages being sent from the brain to the body, and from the body to the brain. How severely a person will be affected by CP depends on where and how much of the brain has been injured. CP affects each person differently.

CP can range from a slight awkwardness in movement or coordination to a complete lack of muscle control that affects all movement and speech; however, the affects of CP are usually somewhere in between these two extremes. It is important to remember that the degree of an individual's

physical disability does not indicate their level of intelligence or their ability to learn.

CP is known as a developmental disability because it affects a young child's ability to meet predictable developmental milestones, but CP is not considered a progressive condition. Damage to the brain is a one time event that does not worsen over time; however, secondary or associated conditions may sometimes develop.

CP is not communicable, not a disease, not hereditary and not life threatening. Currently, CP has no cure, but early diagnosis and therapy can support individuals as they learn to compensate for their disability and achieve their goals.

CAUSES

Cerebral palsy results from injury to the central nervous system of the brain during pregnancy, at birth or up until the age of three. This damage may result from many possible factors including developmental disorders, injuries or diseases. The severity of the damage depends on the type and the timing of the brain injury.

A large number of risk factors have been identified that can produce CP. These risk factors are not causes. They are variables that alone, or in combination, can increase the chance of an individual being affected by CP; consequently, a risk factor may contribute to CP, but the absence or presence of a risk factor does not mean that CP will or will not occur.

For about 70% of children with CP, brain damage occurs before birth. During pregnancy, any risk factor that produces a low birth weight can increase the likelihood of CP. These factors include multiple births, a damaged placenta, infection, poor nutrition, maternal diabetes, premature dilation of the cervix, blood incompatibility or sexually transmitted diseases.

For about 20% of children with CP, the brain injury occurs during the birth process. During labor, risk factors that can increase the chance of

damage to an infant's brain include a premature delivery, a difficult delivery due to abnormal positioning of the baby, a rupture of the amniotic membrane leading to fetal infection, a prolonged loss of oxygen or severe jaundice.

For about 10% of children with CP, the brain injury occurs after birth. In early childhood (0-3 years), CP can result from brain infections like bacterial meningitis or viral encephalitis, or from head trauma sustained in an accident (fall, car accident, abuse), lack of oxygen or seizures.

DIAGNOSIS

When children do not meet anticipated developmental milestones, such as rolling over, sitting, crawling, smiling or walking, parents and caregivers are often the first to suspect that something is wrong. In addition, parents and doctors may begin to suspect a child is affected by CP when the child appears unusually floppy or stiff, lacks alertness, is lethargic, displays jitteriness or trembling, has an abnormal high pitched cry, has problems sucking/swallowing, has low muscle tone, suffers seizures or displays asymmetrical body movements.

Diagnosing CP can be a very lengthy process that can require a child to be monitored over a period of time. The diagnostic process includes doctors examining an infant's motor skills, medical history, physical development, muscle tone, posture, reflexes and hand preference.

To diagnosis and determine the cause of CP, doctors may order specialized tests called CAT scans (Computerized Axial Tomography) and MRI (Magnetic Resonance Imaging) tests that can identify lesions or damage in the brain; in addition, doctors can request CT (computed tomography) tests that can determine underdeveloped areas of the brain. While tests allow doctors to identify children who may be at risk for CP, doctors are hesitant to make a confirmed diagnosis before a child reaches at least 18–24 months.

Doctors may delay making a final diagnosis and/or prognosis for two main reasons. First, a baby may show signs of CP, but the symptoms may be the result of an immature nervous system that can stabilize or mature by the age of two or three. Second, a young child's central nervous system possesses a *plasticity*, or ability to repair, that can sometimes result in a partial or full recovery from a brain injury. This diagnostic waiting period can be particularly stressful or frustrating for parents who realize that their child is not developing at the same rate as the child's peers.

TYPES

While CP affects everyone differently, individuals are classified as having a particular type of CP. Cerebral palsy is classified according to the type of movement disorder and the number of limbs affected. Classification is useful as a label, but it only serves to describe the type and extent of the CP—not to describe the individual person.

Classification reflecting the type of movement disorder includes *Spastic CP* characterized by stiff contracted muscles, *Athetoid CP* characterized by involuntary and uncontrolled movement, *Ataxic* CP characterized by poor coordination, balance and depth perception, and *Mixed CP* combining two or more types of movement disorders.

Classification reflecting the number of limbs involved includes *Monoplegia* involving one limb (usually an arm), *Triplegia* involving three limbs, *Hemiplegia* involving one side of the body, *Diplegia* involving all four limbs but both legs are more severely affected than the arms, and *Quadriplegia* involving all four limbs.

It is important to remember that the limbs affected by CP are not paralyzed; therefore, limbs affected by CP remain sensitive to pain, heat, cold and pressure. It is also important to remember that even if a person is severely physically affected by CP, the individual's ability to learn and/or participate may not be affected.

OTHER CONDITIONS OFTEN ASSOCIATED WITH CP

While not all individuals with CP experience associated medical or related disorders, some people experience associated conditions that can affect their physical and/or intellectual growth and development. Individuals with mild forms of CP are less likely to experience associated conditions than are individuals with more severe forms of CP.

The most common conditions associated with CP include speech or swallowing problems, seizures and intellectual delays. Problems with chewing and swallowing result from weak or uncoordinated muscles in the mouth and in severe cases an individual may require tube feeding. About 30–50% of children with CP have seizures, and these seizures generally begin between 2 and 6 years of age. In addition, between 25–60% of children with CP have some intellectual or cognitive delays that often present more challenges for the individual than the CP.

In addition to the above conditions, a person with CP may experience learning disabilities, attention deficit hyperactivity disorder (ADHD), speech problems, vision impairment, hearing loss, dental decay and other sensory impairments.

RESEARCH

Research is important in understanding, preventing and improving the quality of life for people living with CP. Current research focuses on ways of improving methods of mobility, communication and well being for those living with CP, eliminating or minimizing the factors that predispose the developing brain to injury, exploring ways to protect the fetal and newborn brain, examining why low birth weight in full term and premature babies presents risk factors for CP, developing ways of diagnosing it before or shortly after birth, determining which treatments are most effective,

exploring the effects of aging on people with CP and determining if lost or damaged brain cells can be replaced or repaired.

HOW MANY PEOPLE HAVE CP? DOES IT AFFECT EVERYONE THE SAME?

Cerebral palsy is one of the most common causes of permanent disability in children and appears to equally affect both males and females. It is difficult to estimate the number of people affected by this condition because many people with mild forms are never diagnosed and other people may have multiple disabilities that overshadow their CP.

In Canada, it is estimated that one out of every 500 babies, and up to one in three low birth weight babies, are affected. It is believed that this number is increasing due to medical technology that increases the survival rate of low birth weight babies. The Cerebral Palsy Association of BC estimates that there are over 50,000 Canadians with CP.

Physically and intellectually, CP affects everyone differently. Physical disabilities can range from minimal to severe, and intellectual functioning can range from no delay to severe delay; therefore, the range of the disability is as diverse as the individuals that are affected. For people living with this condition, physical or intellectual limitations may sometimes be unavoidable, but personal choices, opportunities and positive attitudes are essential to minimizing the challenges presented by CP.

FOR FURTHER INFORMATION ABOUT:

Causes and diagnosis: *http://www.fcip.ca/CP/Q&A.htm#Causes* Conditions associated with CP: Children with Cerebral Palsy: A Parent's Guide 2nd Edition (see references).

CP Prevention: *http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm*

Current CP Research: *http://www.ninds.nih.gov and http://www.ofcp.on.ca/outlookn.html#Z6* Risk factors and Types of CP: A guide to Cerebral Palsy at *http://www.bccerebralpalsy.com/pdfs/guidetocp.pdf* or available in print from the Cerebral Palsy Association of B.C.

ADDITIONAL RESOURCES:

Cerebral Palsy Association of BC
801–09 Granville St.
Vancouver, BC V6C 1T2
Tel: 604 408 9484 Fax: 604 408 9489 Toll Free: 1 800 663 0004
Email: info@bccerebralpalsy.com Web: www.bccerebralpalsy.com

National Institute of Neurological Disorders and Stroke
P.O. Box 5801
Bethesda, MD. 20824
Voice Mail: 1 800 352-9424 or 301 496 5751 TTY: 30 468 5981
www.ninds.nih.gov

Ontario Federation for Cerebral Palsy
1630 Lawrence Ave West, Suite 104
Toronto, Ontario M6L 1C5
Tel: 416 244 9686 Fax: 416 244 6543
Email: info@ofcp.on.ca Web: www.ofcp.on.ca

United Cerebral Palsy (UCP National) (2005)
1660 L Street, NW, Suite 700, Washington, DC 20036
Phone: 800 872 5827/202 776 0406 TTY: 202 973 7197 Fax: 202 776 0414
E-Mail: webmaster@ucp.org Web: http://www.ucp.org

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NINDS Cerebral Palsy Information Page: *What is Cerebral Palsy? Is there any treatment? What is the prognosis? What research is being done?*

Ontario Federation of Cerebral Palsy *http://www.ofcp.on.ca*
Understanding Cerebral Palsy: What is CP? Types of CP? Causes of CP? Aging & CP. Guide to CP.

United Cerebral Palsy (2005) *http://www.ucp.org*
Cerebral Palsy—Facts & Figures. What is cerebral palsy? History What are the effects of cerebral palsy? What are the causes? Are there different types? What are the early signs? How many people have cerebral palsy? Can it be prevented? Can cerebral palsy be treated? Is research being done on cerebral palsy?

Spina Bifida

My three year old daughter was born with spina bifida (SB). She has the myelomeningocele type. Three years ago, my so-called perfect world came crashing down. My husband and I waited several years before we finally became pregnant. We learned very late in the pregnancy that our daughter was going to be born with SB.

Neither one of us had ever heard of spina bifida and therefore did not know what it was. Over the next two weeks, I think that I cried more than most people do in a lifetime. The day came that our beautiful little girl was born. She had a closed sac on her back about the size of a plum. She was delivered vaginally and the sac did not rupture.

She was taken immediately after birth to the ICU. She was then transferred the next morning to the children's hospital for her back closure. I did not get to hold my daughter until she was three days old. I was so scared, and I had emotions running through my body that I had never experienced before. The doctors told us that she had nothing—no movement, no feeling from her knees on down.

My world once again went dark. Of course, we could not help ourselves in asking the obvious: Would she ever walk? The one thing that I have found out about SB doctors is when they are asked that question, most of the time the answer is very vague—if you can even get an answer. My daughter also has hydrocephalus and does have a shunt. She had one shunt revision when she was 13 months old. She stayed in the hospital for the first 10 days of her life. She is level L4.

When she was 18 months old, she had surgery on her right foot. She was having problems with the foot turning in, so the orthopedic surgeon performed a right posteromedial release with fractional tibialis posterior lengthening (basically, the tendon running along the inside of her foot was lengthened). She started to crawl when she was about 10 months old and since then, has

continued to do very well. She has no feeling in her feet, and only has a small amount of movement in her feet. She walks with AFO's and a twister cable on her right leg. She started walking independently when she was 28 months old. In the past three years, I have learned so much about spina bifida and met so many wonderful new friends. I want to know everything there is to know to help our daughter be the best she can be. My daughter has taught me so much about life. She has shown me how to love unconditionally, and to see her for who she is, not what she has. She also has a wonderful grandma and grandpa who love her very much. Today, she is just my daughter and I love her dearly.

—DEBBIE DUCKWORTH, Disorder Zone Archives

WHAT IS SPINA BIFIDA?

Spina bifida (SB) is a neural tube defect which is permanently disabling. It affects one out of every one thousand infants each year; however, if the parent has SB or has a child with SB, the recurrence rate increases to one out of one hundred. Anybody can have a child with spina bifida. Approximately ninety percent of all babies born with it have no family history of the defect. Spina Bifida occurs from an incomplete closure of the fetus' spine during the first month of pregnancy.

Infants with SB often have an opening on their spine where the spinal cord may protrude outside the body. Because of the opening in the spine, the nerves of the spinal cord may be damaged. A spinal cord that's damaged may not be able to send and receive messages to and from the brain.

The person may not be able to move their muscles the way other people do. This is called paralysis, which means a person can't move some muscles or feel things on some parts of the body. The defect may occur at any level of the spinal cord, but it most commonly affects the middle or lower back. The degree of the impairment usually is related to the location of the defect. The higher the opening is on the back, the more nerves are affected and the more paralysis there is. Some children will walk with little or no help and

others will use a wheelchair.

Since the spinal cord does not form and close properly, other defects may happen in the nervous system such as little to no bowel and bladder function, spinal problems, respiratory and swallowing difficulties, *hydrocephalus*, and *Chiari malformations*. Eighty-five percent of children with SB have hydrocephalus, an accumulation of spinal fluid around the brain, which must be treated with a shunt (tube); it is surgically implanted into the spinal cord to drain excess fluid.

Children with SB also commonly have a Chiari malformation, Type I or II. Chiari malformation is a benign structural problem that affects the cerebellum, essentially there is extra cerebellum crowding the brain stem and spinal cord. This may or may not cause problems. Ultrasounds, and prenatal testing of maternal alpha fetal protein levels help in making the diagnosis of SB. But sometimes it is not known until birth.

FEATURES AND CHARACTERISTICS

There are three main forms of SB, ranging from mild to severe. Spina bifida *occulta* is also known as hidden SB because it can go unnoticed. When a child has spina bifida occulta, the opening in the back is covered by muscle and skin and the spinal cord is usually not damaged. There may be some problems with the spine, or none at all. Sometimes a small hair growth, a dimple, birthmark or a collection of fat may be seen on a newborn's skin above the spinal defect. It is the most mild form of SB and often people are unaware they have this as it shows no symptoms of the condition.

Another type of SB is *meningocele*. It is a more serious, and rare type of SB in which the protective covering around the spinal cord is pushed out through the opening in the vertebrae forming a sac or cyst. The spinal cord remains normal and a child with meninocele usually has no problems. They will need surgery to prevent any nerve damage later in life.

The last type of SB is *myelomeningocele*, which is the most common and most severe type of SB. When a baby is born with this type of SB, he/she will have a sac protruding from the opening in the spine that contains nerves

and part of the spinal cord. A child with myelomeningocele will have some paralysis because the spinal cord didn't develop correctly and some nerves may have been damaged. A child with this type of SB most likely will use crutches, leg braces or a wheelchair to get around. Approximately eighty percent of children with SB will have learning disabilities, but most have normal intelligence. Most kids with SB have difficulties with their bowel and bladder control.

CAUSES

Nobody knows for sure why kids are born with SB, however, doctors and scientists have some possible reasons. They've learned that folic acid is very important for healthy development of the fetus and is believed to help the neural tube close. Folic acid is one of the B vitamins that is found in foods like broccoli, egg yolks, oranges, and spinach. Research shows that folic acid reduces the risk of having a child with SB and other neural tube defects by up to seventy percent. If you are taking anti-seizure medication, have diabetes, have a child with SB or you have SB, you will need extra folic acid before you become pregnant to decrease the risk of having a child with SB. Some researchers believe that a high fever or viral infection early in pregnancy may trigger SB. Scientists are studying the roles that genes, medicines, and certain chemicals that might play in causing SB.

TREATMENTS

There is no cure for SB because the nerve tissue cannot be repaired. Children should be watched for signs of hydrocephalus, tethered cord, seizures, obesity, bowel and bladder difficulties, urinary tract infections, learning disorders, emotional and psychosocial problems. Medical and surgical treatments are available to children with SB.

Surgery is often done soon after birth to minimize the risk of infection to the exposed nerves and to protect the spinal cord from additional trauma. If the child has hydrocephalus, an accumulation of spinal fluid around the

brain, doctors will put in a shunt (tube), a device that drains excess fluid in the brain.

Another treatment for SB is prenatal surgery, an in-utero closure of the lesion. Surgeons lift out a pregnant mother's uterus on to her abdomen; they then cut into the uterus and repair the fetus' spinal cord. This surgery takes place between the nineteenth and twenty-fifth week of pregnancy. Treatments for SB may include surgery, medication, and physiotherapy.

Many children with SB will need assistive devices such as braces, crutches and wheelchairs. Therapy, medical care and surgery may be necessary to prevent and manage complications throughout the child's life. A child with SB may also need surgery on the feet, hips, or spine. Standing prevents contractures and strengthens the leg bones. If the child does not have the muscle strength to stand, aids such as gaiters or forward lean standers may be used.

Kids with SB may need to see a team of medical people such as occupational therapists, orthopedists, pediatricians, physical therapists, and surgeons. The goal of treatment is to allow the child to achieve the highest possible level of function and independence.

CARING FOR A CHILD WITH SPINA BIFIDA

Parents of children with SB often receive support from a medical team that may include a neurosurgeon (brain doctor), orthopedic surgeon (bone doctor), occupational and physical therapists, pediatrician (child's doctor), rehabilitation specialist, social worker, urologist (urinary doctor) and more. The goal is to create as normal a life as possible. Many children with SB will need support with bowel and bladder management, including catheterization.

Children with significant bowel impairment may have severe constipation, which requires a high-fiber diet, laxatives, enemas, or removal of stool by hand, to avoid bowel blockage. The child may need help with physical therapy exercises, such as foot or leg stretches. It is important to move each joint in the lower limbs through full range of movement everyday to prevent joints from developing contractures. Positioning an infant or child can help correct and

prevent contracture and deformities. Be aware of urinary tract infections, if a child with SB experiences, fever, pain in the lower abdomen, pain during catheterization, or nausea call the child's doctor. A doctor should look at any pressure sores a child may get as they can easily become infected. Extra care should be taken to avoid latex products because children with SB are often allergic to latex.

School is important for learning, developing skills and social interaction. Individualized educational planning and provision of special education and related services can be very helpful in promoting learning. Learning and personal strengths should be emphasized and built on to counter-balance learning weaknesses. Focus on the child's abilities, rather than the child's disabilities.

Professionals and families must work together as an effective partnership. Children with SB should be encouraged to participate with their peers in activities, clubs, and teams to the best of their abilities. They should also be taught to take on responsibility for their own care as much as possible to learn independence.

PROGNOSIS

Life with SB is not exactly the same for each child. But for most, it means taking extra care of their bodies and paying attention if something seems wrong. It can mean taking longer to do things, because braces, crutches, and wheelchairs aren't as fast as walking and running.

Most children with SB can perform successfully in a regular classroom; however, they may need to be evaluated for learning disorders. These children should be encouraged, within the limits of safety and health, to be independent and to participate in class activities as well as modified sports.

Many children are able to achieve social continence with self-catheterization and mobility with braces, wheelchairs and scooters.

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Spina Bifida and Hydrocephalus Association of Canada. *http://www.sbhac.ca/index.php?page=main*

OTHER RESOURCES:

International Federation For Spina Bifida And Hydrocephalus. *http://www.ifglobal.org/home.asp?lang=1&main=1*

Spina Bifida and Hydrocephalus Association of Quebec. *http://www.spina.qc.ca/en/spina_types.htm*

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Section 5 E

Neurological Disorders

Acquired Brain Injury

My family loves me for what I was, and protects what I am. My friends cherish what I was, and often forget what I am. I remember who I was. I want to find out who I am. It is now ten o'clock. At least I know where I am.

— BRYANT, 1992 in Stoler & Hill, p.249

Acquired brain injury (ABI) is an injury to the brain that has occurred after birth. It can be divided into two categories:

TRAUMATIC: resulting from an *external* force applied to the head/brain

NON-TRAUMATIC: resulting from an *internal* source that inflicts injury to the brain

The specific symptoms or loss of functioning depends on which areas of the brain have been affected. Causes of acquired brain injury include:

- Airway obstruction
- Electrical shock or lightening strike
- Trauma to head and/or neck
- Heart attack, stroke, aneurysm
- Infectious disease, intracranial tumors
- Toxic exposure
- Vascular disruption
- Traumatic brain injury with or without skull fracture, blood loss from open wounds, shock, artery impingement from forceful impact

RECOVERY AND REHABILITATION

- Relearn skills and tasks that were mastered prior to injury
- Learn new skills to perform tasks in a different way
- Adjust and modify personal goals, expectations and environments to reflect the change of ability that has occurred since the brain injury

A person's reaction to their brain injury and their ability to cope with problems and impairments is a major factor influencing the success of their recovery.

LONG-TERM CONSEQUENCES

Brain injury results in three major types of impairments:

1. Physical
2. Cognitive
3. Behavioural

Previously acquired skills may be lost and learning new skills that require hand eye coordination may be difficult.A person may display significant problems in areas of attention, concentration, and memory.

Typically, short-term memory (the ability to store information for immediate recall) is most affected. Long-term memory may also be affected.

A person may experience difficulties with language and communication. Processing parts of written and spoken information may be difficult.Expressive language may be affected in ways such as pronunciation, grammar, or meaning and retrieval of words.

Another area affected is the social, behavioural and emotional aspect of a person's life. They may experience difficulties relating to peers and understanding appropriate behaviour in social settings. They may have an increase

in mood swings, a decrease in anger control and frustration and a lack of ability to cope with stress.

The person affected may also experience an increase in depression, anxiety, and loneliness.

POTENTIAL CHALLENGES FACED BY A STUDENT WITH ABI IN A CLASSROOM

Some of the potential difficulties for students with ABI include:

- Attention
- Motivation
- Initiation
- Processing speed
- Abstract thinking
- Expressive and receptive language
- Memory
- Reasoning
- Strategic thinking
- Self monitoring

A student with ABI may face behavioural, emotional and cognitive challenges in the classroom. He may experience problems keeping organized, processing information and producing responses at the same rate as typical students. Other challenges could include the inability to filter out distractions, to stay on task and maintain attention. A student with ABI may exhibit signs of frustration and aggression as well as depression. He may also have a poor self-image and poor social skills and may easily misinterpret social cues.

EFFECTIVE TECHNIQUES AND STRATEGIES FOR WORKING WITH ABI STUDENTS

- Avoid over stimulation so that the student doesn't become agitated or confused
- Be consistent in order to improve memory, reduce confusion, and promote emotional control
- Give step by step directions which reduces confusion
- Talk to the person at the level appropriate to their age and understanding
- Avoid stressful situations as people with a brain injury are particularly sensitive to stress
- Allow longer response time
- Try to incorporate repetition of information to enhance learning and memory
- Emphasize the use of calendars, agendas, communication books
- Reduced course load
- Demonstrate information in more than one way (auditory, visual, hands on)

RESOURCES

www.abieducation.com resource binder Educating Educators about ABI- ch. 2&3

www.bced.gov.bc.ca Special education

www.betterhealth.vic.gov.au Topics A-Z Fact sheet

www.brainconnection.com Brain Injury Association

www.bisusa.org Causes of brain injury. Types of brain injury

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www.show.utoronto.ca

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www.obia.ca/projecthg.html
www.faculty.washington.edu/chudler/interr.html
www.cbic.ca

Attention-Deficit/Hyperactivity Disorder

Matthew, a grade four student, has a hard time getting started on his journal every morning. He loses his pencil and can't find his notebook, usually due to the mess in his desk. As a result, he often wanders around the classroom to borrow things, and in the process, forgets what he was supposed to do in the first place. He rarely completes written assignments. His mother has recently mentioned to the teacher that getting Matthew out of bed and ready for school in the morning is getting harder and harder everyday. He complains that 'none of the other kids like him'.

—MINISTRY OF EDUCATION: Special Education: Teaching children with Attention-Deficit/Hyperactivity Disorder

Cameron, a grade nine student, is the life of the class. He always has an interesting story to tell, rarely related to the subject being studied. He gets along so well with his peers that no matter where the teacher places him in the classroom, he spends more time socializing than working on the assigned tasks. Teachers, as a last resort, often ask him to sit in the hall so that others can do their work. Cameron is fascinated with computers and cars and will spend endless hours designing programs, working on his car or reading car or computer magazines. He often misses class on test days, especially when an essay test is expected. He's barely passing language arts and social studies, even though a psychological assessment done when he was in Grade 3 indicates that he has high average ability.

—MINISTRY OF EDUCATION: Special Education: Teaching children with Attention-Deficit/Hyperactivity Disorder)

WHAT IS AD/HD?

AD/HD or Attention-Deficit/Hyperactivity Disorder is a condition affecting children and adults that is characterized by problems with attention and behavior. AD/HD is a neurological brain disorder and it affects between 3–7 percent of school-aged children and between 2–4 percent of adults. AD/HD begins in childhood, and the symptoms usually appear before the age of seven. Children who have AD/HD experience periods of *inattention* and/or *hyperactivity* or *impulsivity*. These children face challenges daily at school and at home. They require help, guidance, and understanding from their parents, educators, and health care providers in order to reach their full potential. AD/HD is one of the most common childhood disorders and is thought to be 3–4 times more common in boys.

CAUSES

Although the exact cause of AD/HD is not yet known, research indicates that it tends to run in families. More than 20 genetic studies have shown that AD/HD is strongly inherited. Although other factors such as prenatal smoking, alcohol, and low birth weight may contribute to a small percent of cases of AD/HD, they are not the cause of the disorder. After extensive studies and research, scientists have determined that AD/HD is a physical neurological disorder.

SYMPTOMS AND CHARACTERISTICS

There are three types of AD/HD:

1. Predominately inattentive (AD/HD-I)
2. Predominately hyperactive-impulsive (AD/HD-HI)
3. Combined type (AD/HD-C)

SYMPTOMS AND CHARACTERISTICS OF THE THREE TYPES OF AD/HD

AD/HD-I	AD/HD-HI
difficulty in giving close attention	fidgets with hands and feet and squirms in chair
poor concentration	has difficulty staying seated
makes careless mistakes	constantly in motion as if driven by a motor
may seem spaced out	difficulty waiting for turn
has trouble following through with instructions	difficulty in being quiet during activities
forgets things easily and loses things	has impulsive behaviour that might be dangerous or thought of as 'bad'
has poor organizational skills often does not complete school work, chores, or other duties	very talkative
avoids tasks that require a sustained effort	runs or climbs about in inappropriate setting
short attention span	
often skips from one uncompleted task to another	
rarely impulsive or hyperactive	
often does not seem to listen when spoken to directly	

AD/HD-C
the child has characteristics of both the inattentive and hyperactive-impulsive types

DIAGNOSIS OF AD/HD

There is no single laboratory test to diagnose AD/HD. A thorough *assessment* is carried out to establish a diagnosis. Many biological and psychological issues can contribute to and mimic symptoms of AD/HD. Professionals must complete an extensive evaluation in order to rule out other causes and to determine the presence or absence of co-existing conditions. To be

diagnosed with AD/HD a child must have at least six out of nine specific characteristics. The problems must be affecting him/her in at least two areas of life and the problems must be present for at least six months. Parents should take their child to the pediatrician or family doctor if they suspect that their child may have AD/HD. Some pediatricians may make the diagnosis themselves; others may refer the child to the appropriate specialist.

TREATMENTS

There is no cure for AD/HD, however, there are treatments that can help manage the symptoms and vastly improve a child's quality of life.

THE MOST COMMON MODES OF TREATMENTS ARE:

- Behavioral intervention at home and school
- Medication
- Parent education and family support
- Appropriate school programming
- Psychotherapy and counseling support

Treatments should be tailored to suit the unique needs of each child and family. A clinician should also provide periodical follow up appointments for the child.

CHALLENGES AT SCHOOL

Having AD/HD can interfere with making friends at school. A child with AD/HD cannot pay attention or follow conversations properly. Often social cues are missed. He or she may feel *out of the group.* Other children might be intimidated by impulsive or hyperactive behaviour. Those with AD/HD often have a low frustration tolerance and behaviour difficulties

may show up where effort is demanded over a long period of time. A child with AD/HD may appear immature because of inappropriate behaviour. Daydreaming can be a problem.

HELP AT SCHOOL

Developing a classroom routine and structure and avoiding a learning environment that is too busy will greatly help a child with AD/HD. Using behavioural contracts, checklists for required materials, and agendas to keep track of assignments and important dates are all helpful. A child with AD/HD will benefit by being seated at the front of the class, near the teacher's desk (but not separate from classmates) with good role models nearby. Peer tutoring and co-operative learning should be encouraged. Breaking assignments down into small, manageable parts that can be checked, will allow the child to have a feeling of accomplishment without feeling overwhelmed.

AT HOME

It is important for parents to tell their child about AD/HD at an early stage. They should be sure to point out his special qualities and the things that he is good at. They should explain that because of AD/HD some things are hard for him to do, but not impossible. Having a structured routine and being organized with items for a child at home is essential. Parents can set up a system of rewards and penalties to modify a child's behaviour. Frequent and immediate feedback should be provided. Parents should praise their child for improved behaviour and *make an effort to find their child being good* (NIHM, p. 30) while structuring situations in a way that enable the child to succeed. If parents talk regularly with their child's teacher and care givers, the resulting team effort will enhance the chances for the child's positive development and progress.

MISCONCEPTIONS

AD/HD is a result of lax parenting.

FACT: This stems from the thought that AD/HD reflects the behavior of the child, and that AD/HD is not a real medical disorder. The thought is that the child lacks proper discipline and poor behavior is a result. Nothing could be farther from the truth. If anything, the parents of AD/HD children are more likely to be conscientious with their parenting skills than is normal.

AD/HD is over diagnosed.

FACT: Reports in the media have suggested that AD/HD is over-diagnosed in children and that medications are over-prescribed. These reports have since been proven false. Professionals now agree that the rate of diagnosing and prescribing is merely catching up with the actual incidence of AD/HD.

AD/HD is caused by too much sugar and food additives.

FACT: There was once a theory that refined sugar and food additives could make children hyperactive, but after extensive research, the National Institutes of Health, (NIH) concluded that a sugar and additive restricted diet only helped about 5% of the children with AD/HD, really only the ones with food allergies.

Children outgrow AD/HD by their teens.

FACT: In some of the children with AD/HD the hyperactive symptoms may decrease during the teen years, but the inattention symptoms do not. While some children experience fewer symptoms of AD/HD, others have no change in their symptoms.

Children treated with stimulant medications are more likely to become drug abusers.

FACT: Stimulant medications are not addictive. In fact, studies have shown that adequate treatment of AD/HD may reduce the risk of substance abuse.

PROGNOSIS

Only one-third of children with AD/HD outgrow it, although many adults learn coping strategies and compensate quite well. Without early intervention, children with AD/HD may under-achieve and fail at school. These children may also have problems with social relations and anti-social behaviour. A loving, supportive, and structured environment is essential for personal growth. As the child grows older, hyperactivity may be the first symptom to disappear and in some children their ability to pay attention and concentrate improves. Self control can improve with age and often less medication is required.

IS THERE A POSITIVE SIDE?

Many people with AD/HD are very intelligent and likeable. They are *unusually empathic, intuitive, and compassionate* (Hallowell, Ratey, 1994). They tend to be creative, have high energy levels, are sensitive, and highly affectionate. ~

A Day in the Life of James—a Boy with AD/HD

James, a grade three student, has AD/HD. He has known he has AD/HD since he was in grade one. It helps James to know why he sometimes finds it difficult to sustain his attention, control his impulsivity, or manage to win friends. His parents have told him that although things are sometimes difficult for James, they are not impossible. James has many strengths which his parents and teachers make sure he knows about. He is very intelligent, loves the outdoors, is a great swimmer, is creative, empathic and compassionate. His parents and teachers try to focus on these strengths when they help James.

When James gets up in the morning to get ready for school he follows a pretty strict routine. This routine is the same everyday and helps him to stay on track. Sometimes James has trouble following instructions but because his routine has been the same for so long he can remember what to do. James' mother has all his clothes organized the night before. James knows just where to find them. If he arrives at the breakfast table on time, mother will say, "You did a great job getting ready this morning James". Because James often finds things hard to do this praise from his mother really encourages him.

The TV is never on when James is eating breakfast, this would be too distracting for him and he might not get his breakfast eaten. Sometimes James hops up and down from the table during his meals. His parents firmly tell him to sit down to finish his breakfast and remind him that if he finishes his breakfast on time he will be allowed to ride his bike around the yard before school. Since he loves to do this, James will usually get on with eating. Sometimes it helps him to have the timer on to keep track of the time.

James arrives at school just in time for the bell. His classroom is on the first floor of the school. There are 25 students in his class. The classroom is interesting but not too busy. James' desk is at the front of the room near the teacher. Kate and Marcus sit near him. These children are good role models for James. They are very hard workers and rarely fool around which is good for James because he often gets distracted by students who talk or do not get on with their work in the classroom. James is also away from the windows because he tends to gaze out of them. He is easily distracted by any noise he hears.

Kate, Marcus, and James often work together. Kate and Marcus help James with some of the work he has trouble with. They often have discussions about what they are learning. Kate is very good at keeping the conversation on track. Because James is so creative he often has very good ideas when they do projects together. Kate and Marcus like James' ideas and often tell him so.

James' teacher has developed a very good classroom routine. Everyone knows what they should be doing. This is good for James because he is more likely to fidget and squirm if he has nothing to do. When the teacher is giving instructions to James, she usually stands right in front of him and sometimes gently touches his arm to gain his attention.

James has an agenda which the TA helps him to fill out whenever the teacher gives the class an assignment. This is where he also writes down his homework. There is a spot on each day where his parents can sign to say they have seen the agenda. The TA in James' classroom helps him to break down his assignments into small parts. The TA checks often on each part so that James has a feeling of accomplishment and does not feel too overwhelmed.

At recess James goes out to play. The TA is often out on the playground. She seems to be watching all of the children. Sometimes James does things that are dangerous without thinking. The TA reminds him to be careful. Sometimes the TA organize games for the children. This gives James a chance

to play in a more structured way as other children are sometimes put off by his wild behaviour.

When James is getting ready to go home for the day, the TA goes over a checklist of all the things he needs to bring home with him. His mother will use this checklist at home to make sure that all the things go back to school with James the next day. The teacher, TA, and James' parents really work as a team to help him.

After school James goes to the swim club. He really enjoys this and is very successful at it. It is better for James to be involved in individual, non-competitive sports. When he gets home he usually takes his medicine. For the next hour James has free time and often chooses to play outside. His mother keeps a close eye on him to make sure he does not get hurt.

After about an hour the medicine that James has taken will help him to calm down and concentrate. This is a good time for him to do his homework. His mother asks him to show her his agenda. She helps him to organize his work and to do small bits at a time. When he has done something well, James mother makes sure to praise him. The loving and caring environment at home has helped James have high self-esteem. Because of this he is not so frightened of failure and is more willing to take risks. He knows that his parents love him unconditionally.

Before bed, one of James' parents read him story. James finds it hard to sit still, but if he manages to he will get a reward. This encourages him and hearing stories helps him with his own reading and writing.

Life is not always easy for James and his parents. Some days are better than others. James may outgrow AD/HD, but even if he doesn't, he and his parents are hoping that by learning coping strategies he will be able to compensate quite well as an adult.

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Dyslexia

The word dyslexia comes from the two Greek words—*dys,* meaning difficulty and *lexis,* meaning words. Dyslexia literally means has difficulty with words—reading, spelling and writing. Dyslexia is a specific learning disability that is neurological in origin and affects the person's ability to read, write, spell, decode and sometimes understand numbers and math.

The term 'learning disability' describes a neurobiological disorder in which a person's brain works or is structured differently. In studies it has been noted that the side of the brain that usually takes care of things, such as language and reading, does not process the information properly and so the individual is not able to make sense of what they have heard or read. Usually people who have dyslexia have trouble either with auditory processing or visual processing.

CAUSES

The exact causes are not clear; however it is thought that the causes for dyslexia are neurobiological and genetic. Individuals can inherit the genetic links for dyslexia for which there is no cure.

Dyslexia is not caused by or related to lower intelligence. It is not a disease. People with dyslexia do not see backward.

STATS

- 15–20% of the population have a language based learning disability (*www.interdys.org*)
- 70–80% of the students receiving special education with specific learning disabilities are students with disabilities with language(*www.interdys.org*)
- Dyslexia affects males and females equally.

FAMOUS AND SUCCESSFUL PEOPLE THAT HAVE BEEN DIAGNOSED WITH DYSLEXIA:

Leonardo da Vinci · Thomas Edison · Winston Churchill · Hans Christian Anderson · Agatha Christie · Albert Einstein ·Whoopi Goldberg · Walt Disney

EFFECTS

Dyslexia is the most common cause of reading, writing and spelling difficulties.(www.interdys.org) Such language problems can lead to problems in school, the workplace and relating to other people. The impact of dyslexia is different for each person and depends on the severity of the condition. People may have problems with the spoken language when trying to express themselves clearly. Problems can also extend to other areas of life such as math and numbers, memory and understanding of time. Strategies to deal with such problems can be found at *www.interdys.org*.

Dyslexia can also lead to social and emotional problems such as:

- Low self esteem
- Anger
- Anxiety
- Problems with self image
- Depression
- Family problems

HOW CAN PARENTS HELP?

If a parent suspects their child is not developing at a rate that is usually expected, they should take their child to see a pediatrician. Early intervention is best. Parents should be supportive of their child, respect their feelings and understand that it is not a lack of motivation, sensory impairment, inadequate instruction, low intelligence, or other limiting conditions on the part of their child that is causing them to take longer to reach certain milestones.

Parents need to learn the effects of dyslexia and effective techniques to teach their child how to become an independent and responsible person.

Common signs of dyslexia in preschool children:

- May talk later than most children
- May be slow to add new vocabulary
- May be unable to recall the right word
- May have trouble learning the alphabet

Common signs of dyslexia in K to 4th grade students:

- May be slow to learn the connection between letters and sounds
- May have difficulty decoding single words in isolation
- May have trouble remembering facts
- May confuse small words such as at and to
- May reverse letters such as d for b, such as pit for tip

For more information on common signs in all ages please see *www.idabc.com*

The schools and school boards have school aged children assessed only for the purpose of planning instruction, support services and identifying them as a student with special needs. Many children will get identified in school in about the 4th grade. To assess for dyslexia a level C assessment is required to be administered by an educational psychologist. After the final assessment occurs parents should make sure that they have all the information and are well prepared to attend their child's IEP (Individualized Education Plan) meeting. See the government of BC website for information on the process (*www.bced.gov.bc.ca*).

IN THE CLASSROOM

As an educator it is important to understand that children with dyslexia

learn differently and may need the program adapted. Respect the student and don't treat them differently in front of the class. Find out what works for that student and help them by working with them.

People with dyslexia learn best through simultaneous visual, kinesthetic-tactile and auditory teaching. One method that is well accepted and has been used since the mid 1920's is *multisensory teaching* where the educator consistently uses links between all three senses to help the student learn to read and spell.

Parents and educators of a child with dyslexia need to monitor the social and emotional aspects of the child's life and address any issues that may occur and help the child work through them. It is important to focus on the strengths of the individual and remind them that academic success is just one aspect of their life.

ACCOMMODATIONS IN THE CLASSROOM SETTING:

- Use a tape recorder
- Simplify written directions
- Present a small amount of work
- Highlight essential information
- Provide extra practice material
- Develop reading guides
- Place student close to the teacher
- Allow use of instructional aids
- Provide an outline of the lecture

People with dyslexia often show special talents in areas that involve creativity such as art, athletics, architecture, graphics, electronics, mechanics, web design, music or engineering.

A Day in the Life of Taryn— a Girl with Dyslexia

Meet Taryn, a rambunctious fun loving ten year old. She likes to run and play outside, climbs trees and loves soft ball. Taryn lives in Richmond, British Columbia. Last year Taryn was nominated for player of the year in her soft ball league. For Taryn, this is extremely special because it is one of the few places she feels like she can succeed and really belong. Taryn falls into a percentage of between fifteen and twenty percent of the population that have a language based learning disability.

Taryn was formally diagnosed with dyslexia when she was eight years old. Her teacher at school saw her struggling and would frequently witness outbursts during which Taryn would proclaim that she didn't like school, had no friends and that she was stupid. Taryn's teacher also noticed that she had trouble reading and writing . She would consistently confuse a d for a b and also would confuse small words such as at and to. These observations were quite surprising because if you were to speak with Taryn, you would find her a highly intelligent young girl. Taryn's teacher was very concerned about the problems that she was observing with the little girl and decided to call a parent teacher interview to formally discuss with her parents some of her concerns and suggest that maybe some testing would help to determine why Taryn was struggling so much.

Ever since she had been in the first grade Taryn had felt very frustrated in school. She would study so hard and she would just not understand or remember. Math was really difficult for her and she would always get less than half on a spelling test. Taryn would dread getting called on by the teacher to read out loud. She was always afraid the other kids were going to laugh when she made a mistake. The one part of the day that she did look forward to was P.E. Taryn was on top of the world when she was in P.E. She could run just as fast as any of the boys and could throw a ball farther than some of them. Physical education was definitely her favourite subject. She would

always get mad at her Dad when he would say, "Now Taryn, you know that you will never make any money with a career in sports. Why don't you study your math a little harder instead of practicing soft ball?"

A few months later, Taryn was formally diagnosed with dyslexia. Her parents were told that there was nothing to worry about. Taryn would still be able to live a successful and happy life. They were also told that dyslexia has nothing to do with Taryn's intelligence, she was a very smart little girl—just needed a little more support to help her to read and write. These supports would include time with an SEA and her classes would be adapted to follow an Individualized Education Plan (IEP). The classes could also incorporate more multi-sensory teaching techniques—techniques that Taryn would find far easier to understand.

Taryn's Mom tried to learn as much as she possibly could about dyslexia. She started to notice the similarities that her daughter had to some of the characteristics that she read about. Taryn's Mom noticed other things that her teacher had not. Taryn had always had trouble with time; she was never able to read a clock. They thought they had solved that problem by just giving Taryn a digital watch.

Taryn's Mom worked on getting the best possible help for her daughter. She took an active role in the preparation of the IEP, hired a tutor for her daughter and would read to her every night. Unfortunately Taryn's Dad did not take this approach. He assumed that Taryn's problems were a result of her not trying hard enough. He would always say to Taryn "you just have to try harder". He would also punish Taryn if she would get a bad grade on her spelling test. He couldn't believe that any daughter of his was "retarded". He blamed himself for his daughter's problem, and he thought it was something that he had done. As punishment Taryn's father withdrew her from the one thing that made her feel good, her soft ball team. Her mother would stand up for Taryn all the time explaining that it wasn't because she was not trying, and it was nothing that he had done wrong. She also explained that over time Taryn would be able to cope on her own. She would eventually learn to deal with her disability. He wanted nothing to do with the extra help for Taryn and demanded that the label that she had been given at school be removed from her file. Taryn's Mom disagreed causing a fight which caused a rift in Taryn's family. Within a few months Taryn's Dad left.

During this time Taryn's IEP was implemented at school. Taryn's teacher started using some of the techniques that were recommended for children with dyslexia. Taryn was allowed to use an instructional aide to help her with her reading. Instruction was also presented in a way that was multi-sensory, which meant that Taryn simultaneously was learning through visual, auditory and kinesthetic methods. One day at school Taryn met Sarah.

Sarah had been assigned to Taryn as her SEA. It was Sarah's job to help Taryn in her classes and help her fit in. Sarah was very concerned with Taryn's low self esteem and the fact that she did not have many friends. Taryn revealed one day that she really liked soft ball and that her Dad had taken her out last season. Since he had left, her Mom hadn't had enough money to enroll her this season. Sarah thought it might be a good idea at lunch time to have intramural soft ball. Perhaps this would be a way to show Taryn her special talents. It might reinforce to her that all people aren't good at everything. The soft ball was a success and Taryn made a new friend.

Throughout the rest of the year, and well into the next few, Taryn struggled with her reading. She managed to master her writing and now recognizes when she gets her b and d mixed up. Today Taryn realizes that she does not have to get the best grades in school as long as she tries her best. Taryn is graduating this year and has been picked to play for the Canadian soft ball Olympic team. She coaches for the Para-Olympics Canadian team. Taryn now has hopes and dreams. She is happy that her mother stood up for her. Taryn hopes that one day her father will accept that she does have a disability but that it does not affect the person she is or will be. She dreams that she will play for the Olympic team, win gold and become a physical education coach.

RESOURCES:

Organizations and Websites:

Davis Dyslexia Association International

Dyslexia—The Gift. *www.dyslexia.com.*
Information about the positives of learning disabilities and specialized teaching methods for people with dyslexia.

The International Dyslexia Association
1 800 222 3123
www.interdys.org
The IDA is an international non-profit organization dedicated to the study identification and treatment of the learning disability dyslexia.

Learning Disabilities Association of BC
Vancouver Chapter
3292 E Broadway, Vancouver BC
604 873 8139
www.ldav.ca
The LDAV is an organization that offers workshops on learning disabilities, offers referrals to local professionals that are specialized in learning disabilities.

BC Ministry of Health Services. *www.gov.bc.ca*
This is a website that gives all the information about the provincial health care system. It also gives information on health topics, medication, medical tests and support groups.

BC Ministry of Education. *www.bced.gov.bc.ca*
This website gives the steps taken in assessment. It also gives information on Individualized Education Plans and what this means for a child with dyslexia. The Website can also offer information on what to expect from your children in each grade level.

National Centre for Learning Disabilities
1 888 575 7373
Provides information and referrals for people with dyslexia.

Dyslexia Research Institute. *www.dyslexia-add.org*
This institute uses the Multi-sensory language education using the Hardman Technique to educate students.

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Fetal Alcohol Syndrome/Effects

I wish I could repair myself; I wish people didn't throw me on the shelf. I wish people wouldn't use me sooo much, I wish people would take advantage of how precious I am. And . . . I wish they wouldn't use too much touch.

NIGEL age 16: (Grafe, 2003)

A FATHER'S THOUGHTS

My son has a very small body stature. He is positive and outgoing and sees the world as a caring place. He finds thousands of ways to get into trouble. My child is somewhat blind—blinded by his ability to sense danger. I hope he will not end up in jail. I wish people would see the potential he has and gently and slowly teach him basic self-preservation methods that the rest of society takes for granted.

—From a father who is sole parent of a boy, 10 years of age affected by FAS. (*British Columbia FAS Community Action Guide*, 1988) pg. 9

Fetal Alcohol Syndrome/Effects (FAS/E) is a syndrome that describes the neurological and physical outcomes for children of mothers who have used and abused alcohol during pregnancy. These children often are endearing and affectionate—qualities which can mask this lifelong neurological disability.

Children with FAS have a smaller than normal head circumference and are often small, with height and/or weight being below the ten percentile. The

child might also have a number of facial characteristics which can include short eye slits, elongated mid-face, long and flattened nose and upper lip, thin upper lip and flattened facial features. The facial features are more noticeable in early childhood and less noticeable during infancy, teenage years and adulthood.

Fetal Alcohol Syndrome can effect the central nervous system causing developmental delays, intellectual disabilities, learning disabilities or attention deficit hyperactivity disorder.

A qualified physician can make a diagnoses, when there is known prenatal alcohol exposure and the child exhibits the previously mentioned characteristics.

DEVELOPMENT AND SCHOOLING

It is important to get an early diagnosis so that a support system can be put into place for the child and parents. Without the appropriate supports the FAS child tends to drop out of school in the later grades.

Common characteristics for those with FAS are: attention and/or memory deficits, problems understanding the consequences of actions, and abstract concepts. Those with this condition are unable to manage money, problem solve, and tend to have poor judgement in regards to life strategies. They also may have lack of control over emotions and exhibit impulsive behaviours. Children with this condition are social and friendly especially in their younger years.

About 85% of children with FAS, have an average IQ and the remainder have an IQ under 70. They are often verbally capable, yet have difficulty learning in school and working at their appropriate grade level—especially after the primary years.

In British Columbia some schools have educational support teams to help with the child's educational needs and social skills. Some children need medication and/or counselling for their behaviours. As teens they

may need vocational training to help them find appropriate jobs. If they are severely affected they may need to live and work in supervised situations.

PREVENTION

According to Canadian research approximately nine babies in 1,000 are born with FAS—the leading cause of developmental disability. Children with FAS can be physically healthy yet they will never outgrow the neurological effects. They can however show some improvement with help and support from their families, communities and professionals. FAS can be prevented by abstinence from alcohol and drugs during pregnancy. ~

SUPPORT GROUPS

SNAP, (The Society of Special Needs Adoptive Parents)
Phone: 604 687 3114 or Toll free: 1 800 663 7627
E-mail: snap@snap.bc.ca
Web site: www.snap.bc.ca

Material is available from: BC FAS/E Support Network
Phone: 604 589 1854
E-mail: fasnet@istar.ca
FAS Link web site: www.acbr.com/fas/faslink.htm

A Day in the life of Kara— a Girl Born with Fetal Alcohol Syndrome

My name is Kara. I am finishing grade eight and attend high school. I turned 14 last month. I am a lot shorter than most of the other students in my class. I have short brown hair, small, wide set blue eyes and a tiny upturned nose. They tell me I have an average IQ, but I have a difficult time learning. When I was born the paediatrician was worried something wasn't quite right with me as I was very small and had a small head. My eyes were small and widely spaced, my face was flat, my upper lip was thin and my nose was short and upturned. After questioning my mother and testing me, it was discovered that I had Fetal Alcohol Syndrome, (FAS). This condition was caused because my mother drank while she was expecting me. I was born with a number of disabilities. No one told my mother she shouldn't drink when she was pregnant and she never told the doctor about it. I don't live with my mother. I live with my adopted mom and dad.

There is no cure for FAS. I will never outgrow it, but being diagnosed early I have always had extra help. Now I'm in high school. I have a Teaching Assistant (TA) , who helps me with my classes. In school I have four classes a day, right now I am taking math, english, cooking and resource. I go swimming on Friday mornings and I go horsebacking riding on Thursday afternoon. In resource I get a lot of extra help with my math and english. I have a hard time in these classes. I have a hard time understaning what I read. It doesn't always make sense to me.

My day starts early with my mom calling me for school. She is very firm. She has a routine posted of what I have to do in the morning; sometimes this makes me angry and I trash my room, but mom and dad just have me go back and do things properly. I find it difficult not to do things like trash my room when I'm angry. Mom and dad don't like it when I break things. They have had to replace some of my furniture. They remind me how important it is to follow my routine so that I will stay out of trouble. When I'm ready, mom or dad checks to see if I have all my things for school. On Friday they give me money for lunch. I take the bus to school and when I get there I go to my locker and then to the resource room where my TA, Ms. Blair, is waiting. She always is happy to see me. I'm glad she is my TA.

Today is Day 1. The blocks are posted on the board. Block A is first today, so that means I had cooking. We made muffins. I like my cooking class, but don't always remember to pay attention to things. My TA reminds me to keep focused on what I am making and the time so my muffins won't burn. She helps some of the other students in cooking. I had a hard time with some of the others as I didn't understand what they meant when they said some things to me, then started to laugh. It bothered them when I got angry and said I was going to kill them, especially since I had a knife. They acted like it was a crime. My teacher told a story about a boy who said that he would kill someone and how wrong it was to say it. The police were called and everyone was afraid of him. People became his friends when he used words like *I'm angry*, and *I don't like that* or *I don't understand* and *can we fix this and be friends*.

Block B is math, on Monday. Mr. Brad taught us how to do some equations and I did very well. On Wednesay we did a quiz and I got my paper back today. I only got half of them right. Mr. Brad and Ms. Blair said that was okay and they would help me figure out why I got them wrong. They said to do them the same as the other questions but they looked different to me. They did try and explain the questions to me.

Today is Friday so I got to go swimming. While we were there two boys started talking to me and wanted me to go with them. Ms. Blair said no and asked them to leave. She said they were in their twenties. I thought they were nice. They said they wanted to show me a good time. I don't know why I couldn't go with them.

I love to swim and really enjoy going to the pool. I wish we could go more often instead of having english. Reading is so hard and I feel so stupid. Everyone seems to understand what Mrs. James is talking about. They get the answers right. Ms. Blair is always telling me to stay on task, but I would sooner be swimming or riding horses. I draw horses in english. I understand them better. I think I would like to work with animals when I grow up.

After swimming today, I got to go to the cafeteria to buy lunch. The lady said I didn't have enough money for three things, only enough for my drink and pizza, not enough for the cookie. I had lots of money I had two loonies and three quarters. When I started to shout at her, two teachers came and took me back to the resource room. Mr. Collier (my resource teacher), said I wasn't allowed cafeteria privileges for two weeks and that I had to apologize. He also explained that to buy pizza, a drink and a cookie I needed four loonies. I had five coins—that is more than four. Mr. Collier said it was not the same as four loonies, that it was less.

Block D was last. I had resource with Mrs. Roberts. She helped me with my math and we worked on some of the book I'm reading for english. I like this book because it's about horses and she let me draw a picture of a horse. It was also Simon's birthday so we had birthday cake for a treat.

I took the bus home, yelled at mom when she asked how my day was and went straight to my room. Dad just came and told me to turn down my music as it was late and time to go to sleep. I think I will climb out the window when they are all asleep, go meet my friends and have some fun. ~

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British Columbia FAS/E Support Network, E-mail: fasnet@istar.ca Phone: 604-589-1854

Pediatric Hydrocephalus

REFLECTIONS OF A SIBLING

Hi! My name is Hannah and I'm the sister of Julia who has spina bifida and hydrocephalus. Right now you are going to find out my feelings about Julia. I have good feelings, bad feelings and okay feelings about her. I hope you'll understand and enjoy my feelings about Julia.

When my mom told me about Julia, for the first time I was scared and I didn't understand. Mom told me all about her, about her shunt and how it works and her back. She also said the doctors would have to close the hole in Julia's back and that her legs might not work right. When Mom told me all those things, I got scared and sad because I didn't want Julia to go through all of this. Not just Julia, but my family too. Really to tell the truth, I thought this was all a dream, but it wasn't.

When Julia was born, Mom told me about her surgeries. I just could not believe Julia went through all of that. I didn't really feel scared anymore, I really felt sorry for her. I also felt happy when she was born because I had a baby sister. Finally!! I already have two wild brothers. And I was happy because I just couldn't wait to see her and also because I never knew a baby that was so tough.

The day came when I was able to see Julia for the first time at the hospital. When I saw her, I thought she was the 'beautifullest' princess there ever was. I also felt scared because she had all these different coloured wires on her. I also didn't understand why they cut her hair on one side. They explained to me that was where the doctors put her shunt in. I looked at her for a long time.

If Julia gets a wheelchair in the future, I have one thing already planned. We are going to the mall and I'm going to push her down those ramps full

speed for fun. She will think that is fun. I really can't wait for Julia to get older because we can do so much together! I also feel sort of scared too because there's going to be a lot of differences. But really, I'm anxious to see what life will be like for her.

Well, those are my thoughts and different feelings about Julia Mae, my beautiful, wonderful, most precious sister in the world!!!!! I love her and I am so proud of her!!!!

—By Hannah *Julia's Journey with Spina Bifida*

WHAT IS HYDROCEPHALUS?

Hydrocephalus is derived from the Greek word hydrokephalon; hydro meaning water and kephalon meaning head. Hence the genesis of such old fashioned terms as 'water head' or 'water on the brain.'

This condition occurs when there is too much cerebro spinal fluid (CSF) surrounding the brain. The causes are numerous. Basically either the body produces too much fluid (communicating) or there is a blockage somewhere (non-communicating) and the fluid can not be reabsorbed. When a child is born with this condition it is referred to as congenital. If the condition happens at some point in a person's life the condition is acquired. CSF is composed mainly of water, trace proteins, electrolytes and nutrients like glucose. It is clear, watery and colourless. Its main functions are to protect the brain and spinal cord from injury, to nourish the brain, help it function normally, and to remove any waste products.

SYMPTOMS OF HYDROCEPHALUS AND HOW IT IS DIAGNOSED

Common Symptoms in infants who are 18 months or younger:

- Abnormally large head (normal circumference at birth is 33–36 cm.)

- Irritability
- Rapid skull growth
- High pitched crying/screaming
- Head bobbing
- Split sutures of the skull
- Distended veins in the scalp
- Loss of vision
- Sun-set/downward gaze (unable to look upward)
- Apnea (breathing stops and starts)
- Bulging or widening of the fontanelle
- Impaired lateral gaze - unable to track
- Weakness or spasticity (increased contractions of the muscles) of the limbs
- Bradycardia (slow heartbeat)
- Frontal bossing (forehead-round swelling or growth)
- Papilledema (edema and inflammation of the optic nerve)
- Poor feeding
- Opthalmoplegia (paralysis of the eye muscles)

Common Symptoms in children who are older than 18 months:

- Frequent headaches (especially late at night or early morning)
- Lethargy or drowsiness
- Awkwardness, stumbling, or difficulties walking
- Vision problems, double vision
- Concentration, mental difficulties, or memory loss
- Nausea and or vomiting
- Unexplained changes in level of consciousness
- Incontinence
- Neck pain
- Irritability
- Abdominal pain
- Behavioural changes

- School performance suddenly declines
- Opthalmoplegia (eye muscle paralysis)
- Macrocephaly (head is abnormally large)

Neuroimaging of the brain is essential for diagnosis and management of hydrocephalus. There are different types of neuroimaging:

- Ultra Sound (mainly for infants under 18 months old; for adults the skull must be opened first)
- Magnetic Resonance Imaging (MRI)
- Computed Tomography (CT Scan)
- Radioisotope Cisterngraphy (available to teenagers and adults—a test used to monitor the flow of CSF and pinpoint a cause of obstruction)

Cerebro spinal fluid sampling, by performing a lumbar puncture, is the most common way to get a CSF sample. It is primarily done to look for infection, determine any brain and or spinal cord damage and check CSF pressure level.

TREATMENTS

First, the neurologist must diagnose the exact cause of the hydrocephalus. Only then can a proper and individualized treatment plan be developed by the health care team.

The primary goals of any treatment are to normalize the CSF level, to prevent and or reverse any brain damage, to avoid complications and lastly, to minimize dependency on a shunt.

The most common form of treatment is surgical. Surgery is performed to either remove any obstructions or create a new CSF drainage pathway.

SURGICAL TREATMENTS

- NEUROENDOSCOPY is a surgical procedure performed in order to remove any obstruction of the CSF pathway and to allow the CSF to flow properly. This operation is performed in the hospital by a neurosurgeon who uses an endoscope which is a highly refined surgical device consisting of a flexible tube, bright light source, camera and instrumentation required for the fine and precise surgery.
- SHUNT SURGERY is the implantation of a system of tubes and a valve within the body in order to create a new pathway for the CSF to drain. The valve is necessary because it controls the rate of the CSF drainage and prevents any back-flow. Shunts need to be replaced for a wide variety of reasons: mechanical failure, insertion of incorrect valve, infections, pathway obstructions, routine replacement or the need to lengthen the catheter because the child is growing.

SOME COMMON SYMPTOMS WHEN THERE ARE SHUNT COMPLICATIONS

- Persistent headaches
- Loss of appetite
- Loss of memory
- Lethargy, drowsiness or coma
- Nausea and or vomiting
- Vision problems
- Abdominal pain or cramps
- Behavioural changes
- Frequent persistent low grade fever
- Redness or swelling anywhere along the shunt tract
- Impaired speech

- Inability to look upward
- Extra sensitive to light/sound
- Unexplained changes
- Easily disoriented even when performing routine tasks

Drug Therapy is usually tried when there is an overproduction of CSF. The goal is to reduce the rate of CSF production and normalize the level.

Spontaneous resolution occurs in rare cases when the body inexplicably heals itself.

Can a pregnant woman prevent the development of hydrocephalus in her fetus?

She can greatly reduce the risk by taking folic acid supplements, getting good prenatal care, taking a daily multivitamin, maintaining a balanced diet, avoiding drugs, alcohol and other chemical pollutants and above all, taking care of herself.

If there is a predisposition to hydrocephalus in your family history, there are a number of prenatal screening tests and evaluations available. These tests greatly increase the chances of identifying abnormalities much earlier in fetal development. Two such tests are the alpha-fetoprotein (AFP) analysis test and the ultrasound.

Babies born prematurely are at greater risk of developing hydrocephalus because many parts of their body have not matured yet and therefore are more prone to damage. Neonatal intensive care, especially for premature babies, has greatly improved over the years thus significantly reducing possible complications.

PROGNOSIS

If left untreated, especially in children older than two years, the likelihood of death is very high and the chances of developing severe and permanent brain damage are great. Young children have brains that are more plastic (the brain can find and develop new neuro pathways) because they are still growing and developing. Until about the age of two, their skulls are still very flexible because the cranial sutures (connection between the bone plates in

the skull) have not yet permanently joined together. As a result the pressure of the accumulated CSF does not impact the brain as quickly or severely.

Children who have difficulty controlling their neck muscles are in greater danger of hurting their heads. There are many special pieces of equipment available to help prevent injury and aid mobility. Most activities are good for children with hydrocephalus and it is important that they are encouraged to participate. In this context, like everyone else, they have lots of opportunities to develop not only social competence and natural peer relationships but also physical skills.

Children with hydrocephalus have an excellent chance of reaching their full potential with good comprehensive medical care, some assistance and programs that stimulate their development. In long term studies, approximately 30% have an IQ in the normal range and about 60% are able to integrate into their neighbourhood school system. Seizures are not commonly associated with hydrocephalus however shunt treatment can cause epilepsy, especially in children younger than two years old.

IMPORTANT THINGS TO KNOW ABOUT THE BRAIN AND SPINAL CORD

The brain is the nerve center of the body and is part of the central nervous system (the brain, brainstem and spinal cord) and the peripheral nervous system (all the nerves). It is the most complex organ in the body and one of the most important. The brain's primary function is to regulate the body by controlling an enormous number of nerves that are connected to all parts of the body. It analyzes, makes decisions and remembers everything you experience. The brain is split into two main hemispheres. The left hemisphere controls the right side of the body and the right hemisphere controls the left side of the body. Each hemisphere is made up of lots of different parts and each has a different job to do. The brain is complicated - no two are exactly the same, not even in identical siblings. The brainstem is located just above the spinal cord and connects the brain to the spinal cord. It controls some of the body's automatic functions and senses: blinking, blood flow, breathing, digestion, hearing, heartbeat, swallowing and tasting. The spinal cord is the bundle of nerves located inside the spinal column which receive and

then send out signals. It reacts to anything basic like temperature, pain and spatial relationships (where the body is located in relation to the things around it). ~

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www.bchealthguide.org, click on BC INFO, search - hydrocephalus

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www.surgery.ubc.ca.neuroprograms.html#hydroceph

Neurosurgery, updated 2004
www.neurosurgery.medsch.ucla.edu

Pre Term Infants, updated 2004
www.cps.ca/english/statements/FN/01-01.htm

Studying neural tube defects: Lessons learned
www.cps.ca/english/CPSP/Studies/neuraltube.htm

FOR ADDITIONAL RESOURCES:

Brain Tumour Foundation of Canada
650 Waterloo Street, Suite 100, London, Ontario N6B 2R4
519 642 7755 · fax 519 642 7192
E-mail: BTFC@gtn.net Web: http://www.btfc.org/

Canadian Paediatric Society
100–2204 Walkley Road, Ottawa Ontario, K1G 4G8
613 526 9397 · fax 613 526 3332
E-mail: info@cps.ca Web: www.cps.c/english/CPSP/Studies/neuraltube.htm

Caring for Kids—Find a Doctor 604 453 8300
Neurosurgery Faculty/UBC Surgery
Room 3100, 910 West 10th Ave., Vancouver, B.C., V5Z 3V4
604 875 4142 · fax 604 875 4036
Web: www.surgery.ubc.ca/neuroprograms.html

Spina Bifida and Hydrocephalus Association of Canada
4480 Oak Street, Vancouver, B.C., V6H 3V4
604 878 7000 · fax 604 677 6608 · 1 800 565 9488
E-mail: sbhabc@shaw.ca Web: www.sbhabc.org

Prader-Willi Syndrome

Over the years we were misguided and misinformed, which led to much confusion as to how to handle her, how to approach her eating habits, how to cope with her temper tantrums. We had many family problems, many debates, and heated discussions. The situation created more disorganized family conditions. Our other three children, who are older than M, would get upset due to our lack of control of her. Our being a very close and religious family had, no doubt, pulled us through some of these difficult periods. Our financial cost, due to her not being diagnosed, is close to one million. Fortunately, most of this was paid by personal medical insurance, but we as parents also paid a large amount. Our health suffered. We had high blood pressure, were depressed, nervous, upset, confused, disappointed, and just plain angry. All three of us struggled … but all three of us never gave up.

—By JACK SHERMAN and GERALD ENTE
From; *A Case Study: A Chronology of Hope Management Of Prader-Willi Syndrome*

WHAT IS PRADER WILLI SYNDROME?

Prader Willi Syndrome (PWS) is a genetic disorder which is typically characterized by low muscle tone, short stature, immature sexual development, cognitive disabilities, behavioural problems and a chronic feeling of hunger that can lead to excessive eating and life threatening obesity. Features vary from person to person but often include small hands and feet, almond shape eyes, a small triangular mouth and centrally distributed obesity.

PWS occurs in all races and in both sexes. It is rarely hereditary (two percent or less). It can occur in any family, but rarely occurs more than once in a family. A person may acquire a PWS-like disorder through injury to the

brain. PWS is assumed to be purely accidental; no blame can be attached to either parents or doctors.

PWS can be caused by more than one type of genetic abnormality. The most common genetic abnormality, which accounts for 70% of people with PWS, is a deletion. This occurs when a small piece of chromosome 15 from the father is missing. Another form of genetic abnormality is maternal disomy, and this accounts for 25–30% of people with PWS. This occurs when two chromosome 15's are inherited from the mother, and none from the father.

The incident rate for PWS is 1 in 15,000. Currently 99.5% of children born with PWS are diagnosed accurately through genetic testing.

HOW DOES PWS PROGRESS?

PWS has two stages. In the first stage newborns with PWS are usually small, weak and floppy. Successful breast-feeding is unlikely because of the baby's inability to suck. The second stage usually occurs between the ages of two and four years of age. The child's appetite increases and the preoccupation with food becomes a lifelong problem.

Hypotonia, or low muscle tone, is evident from birth and continues throughout life. Poor suckling ability may cause the need for the infant to be tube feed, possibly leading to speech problems later in life.

Individuals with PWS have a wide range of intellectual functions with specific learning difficulties, the average being whilst 70. Some may have IQ's almost as high as 100 while others have severe learning difficulties.

WHAT KIND OF MEDICAL AND BEHAVIORAL SUPPORT IS NEEDED?

Early diagnosis is very important, so that behaviour and dietary management can become part of the child's everyday life. Modifications to diet have been successful in controlling weight.

The use of growth hormone therapy to increase muscle tone, motor development, stamina and attention span have shown encouraging results. If started early, height and weight can be normalized, however individuals with

PWS should maintain their energy intake to about 75% of that of their peers. There is an increased risk of scoliosis during growth hormone treatment.

MEDICAL CONCERNS

- Serious medical conditions may go unreported due to high pain tolerance. It is possible for persons with PWS to have broken bones or fractures without voicing discomfort. Note any changes in the child's movement. Check for bruising, as this may be an indication of a fracture.
- Vomiting reflex is absent. Vomiting or pain may be a sign of life threatening injury or ingestion of a large amount of food or even non-food items.
- TEMPERATURE. People with PWS rarely register a fever even when ill. Their temperatures will sometimes be below normal. Even the slightest change in body temperature should be taken seriously.
- SKIN PROBLEMS. Children with PWS are prone to skin picking and as result may form lesions. Children should be monitored for open sores and signs of infection. A body check regimen may be required for some children.

EDUCATIONAL TECHNIQUES

- Use computer or word processing equipment because of hypotonia and writing difficulties
- Use educational programs and video games
- Keep math and science basic

STUDENTS WITH PWS MAY HAVE TROUBLE IN THESE AREAS

- They may be easily distracted
- May not have good sense of time

- They may be anxious about perceived pressure
- They may fixate on one particular part of the task

THE FUTURE

Work experience should be considered carefully. Potential employers should be well aware of the hazards that an individual with PWS faces.

People with PWS are usually people pleasers and are happy to become contributing members of any group. With help, many complete school and achieve in their areas of interest.

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Section
5 F

Special Health Care Needs

Children with Severe Allergies

Hi. My name is Evan. I am six years old and I am in grade one. I can't eat nuts, eggs, wheat or soy. I also get sick from outdoor molds, trees, weeds, grass, dust, cats and dogs. We also think that I am allergic to honey. I feel bad because it makes me sick. I was in a restaurant and I was coughing and coughing and I threw up. I had trouble breathing because someone ate something with nuts and I smelled it. So I coughed and threw up. My mom gave me medicine and then I felt better.

At my school it is nut free in grade K to grade three. The kids up to grade three aren't allowed to bring nuts or anything that might contain nuts. My Epi-Pen is at school. I worry about eating nuts because I would get sick, very sick. I can't breathe when I eat nuts and I could die. I don't want to die.

I went to the hospital when a cat was in our yard. There was some mold by the fence and some dandelions with the fluff on them. I had a rash all over my body. I don't like being sick.

—http://www.angelfire.com/mi/FAST/kidstories.html

WHAT ARE ALLERGIES?

An allergy is an exaggerated immune response to substances that are generally not harmful.
(http://www.shands.org/health/information/article/000812.html)

Most parents ask the question are allergies inherited. *They are*. If both parents have allergies, their child is likely to have allergies. If only one parent has allergies there is a less chance that their child will. A specific allergy is usually not inherited but the tendency to get allergies is.

CAUSES

Allergies are caused by an immune system that is very sensitive; that sensitivity leads to a misdirected immune response (our immune system is responsible for protecting us from bacteria and viruses). There are some allergies that are not harmful and do not cause any immune response. Our body has to be familiar with the substance in order for an allergic reaction to occur. When an allergen enters the body certain cells are released. One of them is called histamine. "Histamine is amine formed histidine that stimulates gastric secretions and dilates blood vessels; released by the humane immune system during allergic reactions." (www.dictionary.refernce.com/search?q=histamine) Once the cells are released, a child starts feeling symptoms. Symptoms can include itching, swelling, mucus spasm, hives, and rashes. Symptoms vary from person to person. A child with food allergies will experience different symptoms than a child with inhaled allergies.

TYPICAL REACTIONS

ENVIRONMENTAL: dust, mould, pollen, grass and trees—*itchy eyes and nose, nasal discharge, blocked nasal passages, sinus headache, sneezing, wheezing, coughing and shortness of breath*

ANIMALS AND BIRDS: fur and feathers—*itchy eyes and nose, nasal discharge, etc.*

INSECTS: stings from bees and wasps—*wheezing, hives, swelling of upper airway with difficulty breathing, swelling of face and anaphylactic shock in extreme cases* (see bee sting allergy, p. 284)

FOODS: eggs, peanuts, nuts, shellfish, milk and wheat (the latter two are common in infants)—*vomiting, diarrhea and bloody stools, plus symptoms as for insect venom (hives, pallor, weakness, difficulties breathing and collapse)*

MEDICATIONS AND CHEMICALS: medical (e.g. antibiotics) and non-medical (e.g. fabric softener)—*any of the above reactions*

—Reprinted from the Canadian Pediatric Society, *Well Beings: A Guide to Promote the Physical Health, Safety and Emotional Well-Beings of Children in Child Care Centers and Family Day Care Homes*. 1992, p. 252 and *p 232. (www.cfc-efc.ca/docs/cccf/00000064.html)

Some allergies can cause life threatening reactions. This happens when the allergen affects the body all at once (called an anaphylactic response).

> *Anaphylactic is hypersensitivity to a substance, such as foreign protein or a drug, that is caused by exposure to a foreign substance after preliminary exposure.*
> *—www.dictionary.refernce.com/search?q =anaphylactic*

Life threatening anaphylactic reactions are mostly caused by peanuts, shellfish and fish. Typical patients with anaphylactic reactions will experience flushing of their skin with hives. Then they will experience swelling in the throat that causes difficulty in swallowing and shortness of breath. With more severe reactions, blood pressure drops and the child can lose consciousness.

Allergies can also affect the lungs causing asthma, the nose causing congestion, or the skin causing eczema and sometimes hives. Asthma causes inflammation in the airways of the lungs and increases the tendency of the muscle around the airway to contract. Children that have asthma feel tightness in the chest, wheezing, cough or shortness of breath.

As a parent, teacher, sibling, cousin, or close friend, it is important to keep in mind that that you can prevent reactions from occurring by eliminating the possibility of exposure to allergens.

THE DIFFERENCE BETWEEN FOOD ALLERGIES AND FOOD INTOLERANCE

Most of the time people think that food allergies and food intolerances are the same thing, but they are actually different. A food intolerance is a food induced reaction that does not involve the immune system. A food allergy does involve the immune system. For example, when a child is lactose intolerant, that means that the child lacks an enzyme that is needed to digest milk sugar. Most of the time the symptoms are gas, bloating and abdominal pain. If a food allergy occurs, the immune system reacts to the particular food as described above. Certain cells are released and a reaction occurs.

WHAT DOES THE SCHOOL NEED TO KNOW? WHAT SHOULD THE STAFF BE AWARE OF?

- The child's medical history
- What the child has allergies to
- The name of any medication that child is taking (the school should be supplied with medication that is not expired and it should be stored properly at room temperature)
- Should know symptoms of an anaphylactic reaction and how to administer proper medication

The school needs a signed copy from the physician outlining any appropriate meal substitutions and an emergency response plan if the allergic reactions is severe. The parents and the staff should sit down and make an individual health plan including preventative actions that can be taken. The staff must be aware of and follow this plan.

RESOURCES

Allergies, reviewed by WILLIAM J. GEIMEIER, MD, last revised, Feb. 2004
http://kidshealth.org/teen/diseases_conditions/allergies_immune/allergies.html

Shands Health Care, Reviewed by A.D.A.M., last revised 2/12/2003
http://www.shands.org/health/inforamtion/article/000812.html

Allergies, reviewed by WILLIAM J. GEIMEIER, MD, last revised, Feb. 2004
http://kidshealth.org/teen/diseases_conditions/allergies_immune/allergies.html

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http://healthallrefer.com/health/allergies-and-genetics-info.html. Are allergies inherited?

Atlanta allergy and asthma clinic—author unknown *http://www.atlantaallergy.com/pdfs/food_allergy.pdf.* What is the difference between food allergies and food intolerance?

http://dictionary.reference.com/search?q=anaphylactic and http://.dictionary.refernce.com/search?q=histamine

Child and Family Canada—Allergies in Children. DEBORAH KERNESTED, RN, Toronto, Ontario, September 2006. *http://www.cfc-efc.ca/docs/cccf/00000064.html*

Chart of typical symptoms and reactions:

In Sickness and Health—Allergies in Children. PAUL V. WILLIAM MD, last revised 1/20/05.
http://www.healthychild.net/articles/sh26allergies.html
What are the causes? What are the symptoms? Are the reactions life threatening?

School Foodservice and Food Allergies: What We Need to Know. (c) 2005
IFIC Foundation *http://www.ific.org/publications/other/allergysheet.cfm*
Shands Health Care, reviewed by A.D.A.M, last revised 2/12/2003
http://www.shands.org/health/inforamtion/article/000812.html

http://www.keepkidshealthy.com/welcome/commonproblems/allergy_testing.html

Juvenile Arthritis

Arthritis—one word, a hundred conditions, and thousands of different stories. If there is one thing we can expect from arthritis, it's the unexpected …

(a brave young man Calgary, AB)

> *My son Kevin has been challenged with three different illnesses for the past several years. Arthritis by far has been the most painful, debilitating and frustrating for him and our family. Kevin continues on being a young teenager. He excels at school, plays underwater hockey and helps whomever he can.*
> *—WHYTE LEANNE, The Arthritis Society*

JUVENILE ARTHRITIS (JA)/CHILDHOOD ARTHRITIS

Juvenile arthritis causes severe joint pain and inflammation, which can mean not being able to get dressed, open a door, or even hold a fork. Arthritis means *inflammation of a joint*. Signs of inflammation are: swelling, heat, stiffness, pain, tenderness and redness.

Juvenile arthritis affects one in 1,000 Canadian children under the age of 16. It is not a hereditary or communicable disease. The exact cause is not known. We know that arthritis is an autoimmune disease, which means that the white blood cells cannot differentiate between the body's own healthy cells and tissues and harmful invaders like bacteria and viruses. So they release chemicals that can damage healthy tissues and cause inflammation and pain. For more information: *http://www.arthritis.ca/types%20of%20arthritis/childhood/default.asp?s=1*

DIFFERENT TYPES OF JUVENILE ARTHRITIS

There are several forms of arthritis but it is broadly classified in three categories :

1. PAUCIARTICULAR ARTHRITIS: affects less than four joints.
   Most affected joints are the knee, ankle, elbow and wrist. Of the children suffering from this type 20% develop inflammation of the iris or uvea which can be detected by ophthalmologist.
2. POLYARTICULAR ARTHRITIS: affects five or more joints.
   It affects more girls than boys and it occurs more often from the age of ten. This severe but quite rare form of JA could begin with only one or two joints, then spread to other joints. The small joints of the hands are affected as well as the weight bearing joints such as the knees, hips, ankles, feet and neck. Sometimes it is accompanied by low grade fever. Bumps or nodules may appear on some areas of the body.
3. SYSTEMIC ONSET ARTHRITIS: affects many parts of the body.
   Children with this condition have spiking (rapidly rising and falling) fever. A rash can also appear during the fever and then disappear by itself. The child appears listless and sick during the fever. This type of arthritis can lead to the swelling of the glands in the neck, under the arms and in the groin. The spleen and liver may also be enlarged. For more information see: *http://kidshealth.org/parent/medical/arthritis/jra.html*

COMMON PROBLEMS

A child can have pain and stiffness due to sitting or standing in one position. Many children suffer from stiffness when they get up in the morning. They get tired very soon after a physical activity. Due to pain and stiffness, children can have difficulty walking and balancing themselves or carrying books and equipment. If they are helped too much they do not feel

independent. When JA flares, it might not be possible for a child to attend school. For more information see: *www.arithrisitsvic.com*

HOW CAN TEACHERS, PARENTS AND CHILD CARE WORKERS PROVIDE SUPPORT?

The following list offers ideas from which to start making necessary adjustments that will allow a child with JA to participate as fully as possible:

- A readily accessible seat, both indoors and out, should be made available to the child should the need to sit arise
- Children with arthritis should be encouraged to move and stretch when they feel the need for it
- They may need to be given extra time or rest periods during time limited activities such as exams
- Computer screens and seats need to be properly adjusted
- It is often beneficial to make the first activity of the day a passive one
- Active and passive activities should be alternated during the day
- Whenever possible, activities should be programmed in the same area or enough time should be given to get from one area to the next
- There should be two sets of books—one for home, one for school
- Ensure that someone (a peer is often an appropriate choice) shares the responsibility of carrying equipment
- In partnership with the child, his or her peers should be educated about JA and its impact
- Discipline for a child with JA should be the same as for his/her peers
- Have the same social, emotional and cognitive expectations of children with arthritis as for others

For more information see: *www.arithrisitsvic.org.au*

AVAILABLE TREATMENT

- Medication is prescribed to control inflammation, relieve pain, reduce fever, reduce symptoms of the disease and assist in the maintenance of the child's normal growth.
- A physical therapist or occupational therapist can provide treatment to help reduce damage to joints and muscles. Children like to keep joints in a bent position which can lead to joint contracture and deformities. Splints can help prevent and gradually correct deformity.
- Exercise helps to reduce pain and joint damage. Therapeutic exercises make it easier for the child to walk and perform other daily activities like opening jars or writing. For pre-schoolers riding a tricycle is an excellent exercise. Swimming is also excellent for most children.
- Children need additional rest when their arthritis is active. Good posture even in bed helps to prevent deformities.
- Children should be encouraged to have a well-balanced diet at regular meal intervals. Food should have a high nutritional value.
- Some children might have difficulty brushing and flossing their teeth. A dentist can suggest various toothbrush handles, electric toothbrushes, floss holders, toothpicks and rinses that will help the child to maintain healthy teeth and gums.
- Eye inflammation may be associated with JA. A regular eye examination is necessary. If arthritis lasts for many years then doctors may recommend surgery.

For more information see: *http://kidshealth.org/parent/medical/arthritis/jra.html*

THE FUTURE

The symptoms of JA eventually disappear in about 50% of children. The

Arthritis Society offers a variety of programs and services that can be helpful. They can reached at 1 800 321 1433 from anywhere in Canada.

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Types of Juvenile Arthritis (*www.kidshealth.org/parent/medical/arthritis*)

Treatment for Juvenile Arthritis. (*http://www.arthritis.ca/types%20of%20arthritis/childhood/default.asp?s=1*), reviewed/updated on : 03/29/2005. (*http://kidshealth.org/parent/medical/arthritis/jra.html*)

How we can support children at home or at school. *www.arthritisvic.org.au*

Stories of children and people with arthritis: *http://www.arthritis.ca/local%20programs/alberta/programs%20and%20services/arthritis%20heroes/the%20many%20faces%20of%20arthritis/default.asp?s=1,* reviewed/updated on : 03/09/2005 *http://www.bcarthritis.ca/AA_OCTOBER/I_Am_Brave.html*, The Arthritis Society.

OTHER RESOURCES AVAILABLE:

Coping With Your Child's Chronic Illness. ALESIA T. BARRETT SINGER, MA, USA

Raising a Child With Arthritis: A Parent's Guide. (Arthritis Foundation, Atlanta, GA, USA)

Your Child With Arthritis: A Family Guide For Caregiving. LORI TUCKER, BETHANY DENARDO, JUDITH STEBULIS, and JANE SCHALLER. (The John Hopkins University Press, Baltimore, MD, USA)

Kids Get Arthritis Too! Hugh MacMillan Rehabilitation Centre, Toronto, ON, Canada

Vision: Arthritis And Your Child's Eyes. The Arthritis Society, BC & Yukon Division UBC Biomedical

Communications, Vancouver. (Video 6 Min. 1991)

We Can: A Guide For Parents Of Children With Arthritis. Arthritis Foundation, GA

Arthritis in Children: A Practical Guide. BARBARA HORGAN, Fontana Books, Australia.

Asthma

Many times, we adapt our lives so gracefully that our children barely notice all the preventive measures we take to control their asthma. We run the air through filters in the furnace, keep the bedrooms clean, change sheets often, watch their diets carefully and give them their medicines. As they get older and are better at listening to their bodies, we adapt again and symptoms seem to subside.

By Sander: A Parent's Guide to Asthma 2001

Asthma is a chronic, inflammatory lung disease that causes breathing problems. It is caused by viral infections and exposure to allergens. It is not contagious and can be controlled. A child with asthma should be capable of participating in most school activities.

SIGNS

- Prolonged cough or chestiness with colds
- Frequent colds, every two to three weeks
- Recurrent croup
- Shortness of breath after exercise
- Recurrent pneumonia

WHO GETS IT?

Asthma tends to run in families. Children with eczema or a food allergy are more likely than other children to develop it.

An allergy to pollen, house dust mites or pets also increases the chance

of developing asthma. Exposure to tobacco smoke, air pollution or other inhaled irritants can also cause asthma symptoms in those with an underlying tendency to asthma.

HOW IS IT DIAGNOSED?

Diagnosis involves all of the following:

- A detailed family and child's medical history
- Physical examination including: chest x-ray, blood tests, sputum studies and allergy prick skin test
- Spirometry breathing test to measure the amount and rate at which air can pass through airways
- Exercise challenge tests and methacholine inhalation tests to evaluate airway responsiveness
- A trial use of asthma medications to see if there is an improvement in symptoms

MANAGING AN ATTACK

If a child exhibits a hunched over posture, tight neck and shoulder muscles, with:

- Chronic, persistent coughing
- Wheezing
- Feeling of tightness in the chest
- Chest discomfort after exertion
- Excessive breathlessness after exertion
- Looks pale, sweaty and agitated
- Has difficulty walking or talking

emergency measures should be taken. If in doubt CALL 911.

DURING AN ASTHMA ATTACK

It is important to remain calm and help the child to relax and breathe slowly. Allow the child to rest in the position in which he has been taught or in which he is most relaxed. Sitting, not lying down, may be preferable as this helps the bronchial passages clear of mucus. If the attack worsens and the child is not responding to preliminary treatment (within 5 minutes or two of bronchodilator treatment), call an ambulance.

SUPPORTING CHILDREN WITH ASTHMA

INDOOR AIR QUALITY (IAQ) AT SCHOOL AND DAY CARE

From about the age of two, most children spend the majority of their waking hours at school or day care; therefore, ensuring that these environments are as free of potential asthma triggers as possible is essential to your child's health.

Irritants and allergens that can affect your child at school often include the following:

- Outdoor smoke, soot, chemicals, pollens, and mold spores
- Indoor mold from ventilation ducts as well as indoor irritants such as tobacco smoke, scents from printers and copiers, and fumes from heating, ventilation, and air conditioning (HVAC) systems

CLASSROOM STRATEGIES

- Parents should inform all relevant school personnel of their child's condition.
- Teachers should meet with the parents and the child early in the school year to determine the child's individual needs.
- The school nurse should be enlisted for training of staff on how to deal with asthma emergencies.
- Parents should prepare an action plan kit. Kit should include information

on the use of medication, its location on student or in school, and specific steps for treatment when a child perceives that an attack is starting. For example, steps on how to use a bronchodialator, different relaxation techniques, and how to use a peak flow meter should be included in kit instructions.

- A school's physical therapist has expertise in chest conditions such as asthma and may be involved in therapy for the student.
- Teachers need to be aware of the student who needs pre-exercise medication and give a reminder if necessary.
- Teachers and staff need to help the child lead as normal a life as possible by encouraging participation in regular classroom activities or ensuring exemption if in the child's best interest.
- The student with asthma should be encouraged to participate in an exercise program, if it is safe for them to do so, to improve physical fitness.
- With permission from parents and child, it would be beneficial to explain to the class what asthma is and how it is treated. Support and understanding from peers will help overcome feelings of isolation, rejection or embarrassment.
- The child should be encouraged to take control of their asthma by using preventive measures to avoid a serious attack.
- Teachers should inform parents of any asthmatic episodes.

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www.canaadian-health-network.ca 2004 The Children's Asthma Education Centre—Managing an Asthma Attack

www.comeunity.com/disability/asthma/bksander.html Introduction quote

www.lung.ca/asthma/diagnosis.html updated Jan 20, 2003 Asthma Diagnosis

www.newtoasthma.com/article/504983.aspx What is Asthma? How can we manage an asthma attack?

ADDITIONAL RESOURCES:

The Lung Association's Asthma Action Handbook
The Lung Association's Asthma Action Helpline 1 800 668 7682
How can asthma be controlled (using a peak flow meter, Asthma Medication, Environment Triggers and Asthma Action Plan)

www.maoclinic.com/invoke.cfm/objectid=87D67A9F-B32-4C73-B42F99D100BE8D13 updated June 03/2004. Asthma Medication

Diabetes

Hello there, all you diabetics!

My name is Lana, I will be thirteen years old (Goody) on February 2001.

I was four years old when I was diagnosed with this yucky disease, and of course I was showing all the signs. Gulping down apple juice and then rushing off to the bathroom, losing lots of weight, etc.

I have type 2 diabetes. I have to take three or four insulin injections a day, as well as five or six finger pokes...

Yes, yes people, diabetes is very annoying but you mustn't let it get the better of you!

Despite my extreme unluckiness of having diabetes, I have jumped horses for four years. I play sports (especially basketball and volleyball), love to shop, play on the web, read and write, design and sew clothes (I plan to be a fashion designer when I graduate), act and sing. I have a fluffy lap dog named Wiggins, and three Japanese Koi fish.

Lana's Story: www.childrenwithdiabetes.com

WHAT IS DIABETES?

Juvenile (type 1) diabetes or insulin dependant diabetes, is usually diagnosed in children and adolescents and occurs when the body's immune system destroys the insulin producing beta cells in the pancreas, resulting in little or no insulin.

Children with type 1 diabetes will look and act normal; however, diabetic symptoms may occur suddenly . They include: unusual thirst, frequent urination, sudden weight loss or increased appetite, extreme fatigue

or lethargy, blurred vision, numbness or tingling in hands or feet, cuts and bruises that are slow to heal, drowsiness and unconsciousness.

Diabetes is diagnosed by measuring blood glucose levels after a person has fasted and drank a glucose rich beverage. Urine testing is useful for monitoring ketones (acids) in the urine indicating possible onset of hyperglycemia.

Diabetes is not contagious. Medic-Alert identification jewelry is often worn to identify a child with diabetes. If blood glucose levels are not controlled, serious complications such as heart disease, kidney failure, adult blindness and amputation can occur.

STUDENTS

Students with diabetes will need a safe and private space to perform self-blood glucose monitoring and/or insulin injections. They will also need a place to store their insulin and an area for safe disposal of their used needles and test strips. A student with diabetes does not want to be treated differently than others and can participate in all school activities.

The student should have a *Child's Individual Care Plan* set up with their school. The plan should contain emergency information such as:

- A plan for communicating with parents
- The specific actions/interventions for school personnel to perform
- School policies
- Procedures for administering and handling medication etc.
- Student's meal and snack times (including additional snack food to have on hand for low or high blood sugar prevention)
- A list of contact phone numbers in case of an emergency
- A description of emergency procedures for handling high and low blood sugar episodes
- The appropriate treatment foods
- Medications

SYMPTOMS AND TREATMENTS FOR A DIABETIC EMERGENCY

School staff should ensure that the student completes all meals/snacks on time throughout the school day and watch for signs of the two most common diabetic emergencies, hypoglycemia and hyperglycemia.

HYPOGLYCEMIA is also called low blood sugar, insulin shock or insulin reaction and occurs if the blood sugar level is too low, usually due to too much insulin, too little food or too much exercise. It can happen within minutes.

Symptoms include: cold or sweaty skin, difficulty concentrating or speaking, dizziness, lack of coordination, headache, nausea, abdominal pain and eventually fainting or unconsciousness.

Treatment DO NOT LEAVE THE CHILD UNATTENDED. Refer to the *Child's Individual Care Plan*. A specific amount/form of sugar should be given. If the child is unconscious, roll them onto their side and call 911 and their parents. DO NOT GIVE ANYTHING BY THE MOUTH.

Parents should be notified of *all* insulin reactions. All reactions should be properly documented.

HYPERGLYCEMIA occurs when the blood glucose levels are too high, usually due to too much food, too little activity, illness, infection or not enough insulin.

Symptoms include: fatigue, extreme thirst, weakness, dizziness, abdominal pain, vomiting and frequent urination.

Treatment: Not usually an emergency situation, but prolonged hyperglycemia can lead to diabetic ketoacidosis where the body is starved for

glucose and starts to use up stored fat for energy. This causes acids to build up in the blood. Ketones (acids) are then excreted in the urine. If a child with Ketoacidosis is left untreated they can lapse into a coma. A student displaying hyperglycemia should have glucose levels checked with test strips and should drink water or a sugar-free beverage as indicated in the *Child's Individual Care Plan*.

Parents should be notified of all insulin reactions and of course all reactions should be properly documented.

MANAGING DIABETES

- Eat healthy and at specific time (i.e. three meals a day, no more than six hours apart)
- Limit sweets and high fat foods
- Drink water or low-calorie soft drinks
- Eat healthy snacks such as fruit, cheese and crackers
- Exercise (often additional snacks will be needed prior to participating in gym and recess, as exercise like insulin can lower blood sugar levels) Exercise can help in achieving good blood glucose levels.

Illness, fatigue, excitement, stress, growth periods, changes in eating habits and hormonal changes can also require insulin adjustments. Frequent blood sugar monitoring, by pricking the finger and analyzing the blood sugar levels through use of a test strip, help determine the correct dose of insulin needed.

Insulin can be given in a number of different ways:

- syringes—with a fine needle tip
- insulin pens—look similar to an oversized pen with a short needle and

cartridge containing insulin. The correct dose is dialed up when an injection is necessary.

- insulin pump—a microcomputer about the size of a pager worn clipped to a belt or waistband. The pump (reservoir or cartridge) holds a syringe filled with insulin that is programmed to release small amounts of insulin through a thin tube that has a needle inserted into the fatty tissue just below the skin (infusion set). The syringe and infusion set are changed every two to three days. ~

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Canadian Diabetes Associations. *www.diabetes.ca*

Children with Diabetes (updated 2000) *www.childrenwithdiabetes.com*

Joslin Diabetes Center (updated 2005) *www.joslin.org.shtml*

Juvenile Diabetes Research Foundation of Canada (updated 2005) *www.jdfc.ca*

Juvenile Diabetes Research Foundation International (updated 2005) *www.jdrf.org*

Epilepsy & Seizure Disorders

Will handles his seizures very well and has as normal a life as possible. He has seizures infrequently most of the year, but in the fall he has flurries that can keep him up all night for many nights in a row. This activity seems to gradually increase over several weeks, has a peak of several weeks, and then slowly decreases in activity until gone. Dilantin seems to help stabilize him, though it doesn't stop his seizures. Ativan helps him get some sleep at night during this period. Will has had no other issues, developmental delays, or side effects from his current medication. He performs at or above grade level in school, participates in most sports, and has compensated for his visual field loss very well. (WILL, age 15 · *http://www.kidsepilepsy.com*)

EPILEPSY

Epilepsy is not a disease and is not contagious. Children who have epilepsy have a neurological disorder that is characterized by seizures. A child's brain is made up of billions of nerve cells that communicate with each other through tiny electrical charges. When some or all of these charges begin to fire together, a surge of energy sweeps through the child's brain causing him to have a seizure.

There are many different types of seizures—generally they vary from child to child. Some children experience starring spells, convulsions, repeated rhythmic jerking and stiffening of the arms and legs. Some types of seizures affect consciousness, cause temporary confusion and even loss of bladder or bowel control. There are even seizures that cause children to drop or fall for no apparent reason.

Specific triggers or events can bring on a seizure. Triggers are unique to

each individual and not all children have them. It is important to try and identify potential triggers and avoid them if possible. Some triggers include:

- Missed dosage of medication
- Lack of sleep
- Excitement or over stimulation
- Anger, stress or worry
- Bright flashes of light, flickering lights of computers, televisions, videos
- Missed meals
- Menstrual cycle
- Food or drinks with preservatives
- Additives such as aspartame
- Loud noises
- Fever, illness and pain

TYPES OF SEIZURES

PARTIAL: occur when abnormal activity takes place in just one part of the brain

AURA: Warning sensation. An Aura is a brief warning that can alert the child a seizure is about to occur. Examples include: an unpleasant taste or smell, tingling sensations, a funny feeling in the stomach, or a visual sensation (seeing colours).

SIMPLE PARTIAL: No loss of consciousness. Symptoms include: uncontrolled shaking, altered emotions, things may look, taste, feel or sound differently, possible speech difficulties.

COMPLEX PARTIAL: Consciousness is altered and children experience memory loss (amnesia). Symptoms include: starring, repeated movements—rubbing, lip smacking, posturing or raising up of one arm, vocalizations and

swallowing. Following seizures children are often confused, sleepy and completely unaware they have just had a seizure.

GENERALIZED: occur when abnormal activity involves most of, or all of the brain

ABSENCE (PETIT MAL): Seizures are brief and not followed by confusion or sleepiness. Symptoms include: starring or spacing out, and there is a brief lapse in awareness. Body movements are subtle.

MYOCLONIC: Symptoms include: sudden jerky movements of arms and legs, typically only affect one side of the body, but can affect both. Seizures are usually short—from less than a second for single jerks to a few seconds for repeated jerks.

ATONIC: Also known as drop attacks. These seizures cause children to suddenly, without warning, drop, collapse or fall down. There are no convulsions with this type of seizure. Consciousness is generally regained after a few seconds and children able to stand and walk again. Close monitoring is necessary because serious injury can result from hitting objects when dropping (i.e. striking head or teeth on tables or desks). Protective headgear is recommended.

TONIC-CLONIC (GRAND MAL): The most intense seizure, often very scary to witness. Symptoms include: loss of consciousness, convulsions, body stiffening and shaking, foaming at the mouth, sometimes tongue biting, and loss of bladder control. A period of confusion and sleepiness generally follows the seizure.

GENERALIZED TONIC CLONIC: This is the most dramatic and frightening to watch. They usually only last a few minutes and do not require medical care. Remember that the child is unconscious and feels no pain.

WHAT TO DO DURING A SEIZURE

Stay calm and protect the child from injury by easing the child to floor and loosening tight clothing—especially at the neck. Remove nearby sharp, hard or hot objects and place a cushion under the child's head. Turn his head to the side so saliva can flow from the mouth.

Never try to restrain child's movements as this could lead to even more violent convulsing. Do not put anything in the child's mouth.

Time the seizure and note its behavior. Call 911 should the seizure last longer than five minutes or if another seizure begins before the first one has ended. *See Status Epilepticus.*

TO HELP A CHILD RECOVER FROM A SEIZURE

Stay with the child and speak gently and reassuringly. Allow the child to rest or sleep following.

Complex Partial Seizures

- Stay calm
- Stay with the child
- Do not try to stop the seizure, let it take its course
- If the child is standing, stay with the child in case they collapse
- Gently guide the child away from danger and remove any dangerous objects
- Speak gently and softly to the child until complete consciousness is regained

Realize that the child may be unaware of his actions and may not be able to hear you. Recovery from a seizure depends on the type of seizure, duration, and the child. It may take seconds, minutes or even hours.

Status Epilepticus

A seizure that lasts more than five minutes, or repeats without full recovery. This is a life-threatening medical emergency—CALL 911

WHEN SHOULD I CALL AN AMBULANCE?

- If it is the child's first seizure
- The child remains confused for more than one hour following the seizure
- The seizure takes place in water
- Normal breathing or consciousness is not restored following the seizure
- The child has sustained another injury
- You should inform the ambulance attendant of the following:
  - Duration of the seizure
  - What the seizure looked like
  - Levels of consciousness
  - Any changes in breathing
  - Bleeding
  - Any injuries

STRATEGIES FOR CLASSROOM INCLUSION

- Children with epilepsy should be treated like every other child They need the same social interaction and behavioural expectations as other children.
- A plan should be in place on how a seizure will be handled should one occur at school.
- Teachers should meet with the student and the parents at the beginning of every year to plan for the student's special needs. Teachers and schools need to be familiar with the type of seizures the student has, what

medications are currently being prescribed, if the student will need to take medication during the school day, and who will be responsible for administering it.
- Teachers need to foster an attitude of understanding and acceptance. Children with epilepsy need support and the other students will need to know how to give it.
- It is important not to hinder a student's emotional and social development. A student needs to be encouraged to participate in activities and develop relationships with peers. Being overprotective can cause fears and lifelong dependency that continues into adulthood.

HOW SEIZURES AFFECT LEARNING

- Children with seizures have the same intellectual capabilities as those without seizures; however, one third of them will not reach their full academic potential due to learning difficulties.
- Epilepsy itself has no effect on intelligence or ability.
- It is important not to make assumptions about a child's capacity to learn. There are many children who live with epilepsy and don't experience difficulties in school.
- Teachers may influence a child's academic development because of reduced expectations due to the misconception that children with epilepsy struggle academically.
- Learning difficulties vary from child to child depending on the type of epilepsy, severity and frequency of seizures, treatment (anticonvulsants, surgery) and psychosocial issues.
- With proper assessment and early educational intervention many learning problems can be reduced.
- Electrical impulses that cause seizures impact the child's cognitive process affecting their brains ability to receive, process, and store information.

Therefore, attention, concentration, memory, capacity for abstraction, language comprehension, motor skills, plus auditory and visual perception are areas that can be effected by seizures and impede a child's academic performance.

TYPES OF SEIZURES AND ASSOCIATED LEARNING IMPAIRMENTS:

Type of seizure	**Associated learning impairment**
Absence	Attention Absence seizures cause short-term loss of consciousness (few seconds) during this time child may miss critical pieces of visual or auditory information
Tonic-Clonic	Attention Auditory perception Problem resolution capacity
Simple Partial	Attention Memory (slight problems)
Complex Partial	Attention Memory problems (more severe) Problem resolution capacity

- Children with poorly controlled seizures, uncontrolled seizures, or experiencing increased seizure activity, may show a decline in academic performance. This is not necessarily permanent. If seizure severity, frequency and duration decline, academic levels may increase. In many cases children may have to re-learn material previously covered.
- Immediately following a seizure a child is generally very exhausted and

needs time to rest or sleep. Children will often fall behind academically because of absence rather than academic ability.

PSYCHOLOGICAL FACTORS THAT AFFECT LEARNING

It is important for teachers and parents to be aware of the psychosocial influences epilepsy has on a child's attitude, behaviour, academic performance and adjustment at school.

- For school age children seizures can be detrimental to self-esteem, confidence and interfere with peer relationships.
- Schools with positive support networks enable children with epilepsy to feel more included.
- Children with epilepsy need to feel that they belong and are valued. They should be encouraged to attend field trips, take gym classes, play sports and become involved in extra curricular activities.
- Peer education can help classmates understand the nature of seizures, reduce teasing or ridicule and counter negative attitudes towards others with epilepsy.

TO AID LEARNING

- For children with *absence* seizures, or children who miss a lot of school due to frequent night seizures, a buddy system is valuable. It enables the student to keep up with the information missed during a seizure or school absence.

Memory and attention

Memory and attention deficits are key areas that effect learning for children with epilepsy. Learning is dependent on attention and for many children

with epilepsy maintaining attention and concentrating for long periods can be challenging.

Strategies to improve attention include:

- Remove possible distractions
- Use interesting material or stimulus to keep child engaged
- Encourage goal setting and use positive reinforcements for achieving the goal
- Pair un-liked activities with liked activities as incentive to stay on task and finish an activity
- Positive reinforcement for staying on task, working through and completing work

Strategies for improving memory:

- Visual aids for children with left temporal lobe epilepsy
- Auditory aids for children with right temporal lobe epilepsy
- Establish a routine for consistency
- Monitor amount of information a child can process—break down information into small pieces and teach in small chunks
- Monitor for changes in consciousness—for children with absence seizures any information or directions given during a seizure will not have been absorbed by the child and will need to be repeated

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ADDITIONAL INFORMATION:

Epilepsy Toronto *http://epilepsytoronto.org*

Mayo Clinic *http://www.mayoclinic.com*

Fraser Valley Epilepsy Society *http://epilepsy.cc*

Epilepsy Foundation *http://epilepsyfoundation.org*

British Columbia Ministry of Education *http://www.bced.gov.bc.ca/specialed/*

ADDITIONAL RESOURCES

Epilepsy—Resource Binder
Fraser Valley Epilepsy Society
3374 Goldfinch Place
Abbotsford, BC
Phone: 604.853.7399
Fax: 604.852.5794
www.epilepsy.cc

Resources available from the Fraser Valley Epilepsy Society:

Epilepsy & Your Child Booklet
Novartis Pharmaceuticals Canada, Inc.
Dorval, Quebec 1997

Teens and Epilepsy Booklet
Edmonton Epilepsy Association 2003
www.edmontonepilepsy.org

A Guide for Parents—Epilepsy
Edmonton Epilepsy Association 2003
www.edmontonepilepsy.org

An Overview—Epilepsy
Edmonton Epilepsy Association 2003
www.edmontonepilepsy.org

Seizures and First Aid—Pamphlet
Epilepsy Canada, Montreal, Quebec 1998
www.epilepsy.ca

Answers To Your Questions—Pamphlet
Epilepsy Canada, Montreal, Quebec 1994

Epilepsy—Avoiding a Medical Emergency
Canadian Epilepsy Alliance, Epilepsy Toronto
www.epilepsymatters.com

Epilepsy—Your Medication for Epilepsy
Epilepsy Canada, Montreal, Quebec 1987
www.epilepsy.ca

Seizures and Epilepsy in Childhood—A Guide for Parents
JOHN M. FREEMAN, M.D., EILEEN P.G. VINING, M.D, DIANA J. PILLAS. John Hopkins University Press, Baltimore, 1997, Chapter: What do you tell the School and Classmates?

Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome

I can't tell anyone at school about it, because when they're cussing someone they say they've got HIV or AIDS. I just ignore it, but sometimes I stick up for the people being teased. The other kids just think that if you've got it, you'll pass it on to the next person you see. It's hard being secretive as well as being ill, but you have to carry on. I wish people knew that you have to go through a lot of things, that having HIV is painful every day.

Living with HIV—Teens Speak Out—Joanne, Age 14
(*www.channel4.com/health*)

WHAT IS HIV

Human immunodeficiency virus (HIV) attacks the immune system, making it difficult for the body to fight infection and disease. Once HIV enters the body, it infects a type of white blood cell called CD4+ cells. These cells are an important part of the immune system that help fight infections. When CD4+ white blood cells are attacked, and eventually destroyed by HIV, the immune system becomes less able to fight infection and disease. HIV is the virus that causes acquired immunodeficiency syndrome (AIDS).

WHAT IS AIDS?

Acquired immunodeficiency syndrome (AIDS) is a disease caused by HIV.

AIDS occurs during the *final stage* of the HIV infection and is diagnosed when you have one or both of the following:

- CD4+ cell count is below 200 cells per micro litre of blood and/or
- an opportunistic infection, such as pneumonia or cancer, develops due to an impaired immune system

SYMPTOMS OF HIV

Early symptoms are similar to other viral infections and can be mistaken for influenza or mononucleosis. This is the first stage, referred to as *acute retroviral syndrome*. Symptoms include fever, sore throat, headache, muscle aches and joint pain. A skin rash may develop along with nausea, abdominal cramps, vomiting, diarrhea, weight loss and enlarged lymph nodes in neck, groin and armpits. Children with HIV show some different symptoms such as delayed growth or an enlarged spleen, as well as developmental delays, kidney and heart problems, sinus and ear infections, flu like symptoms, abdominal swelling, itchy skin rashes, frequent staphylococcus, salmonella, yeast infections, persistent fatigue and weight loss.

ESTABLISHED STAGE SYMPTOMS

After the infection of HIV, it may be many years before seeing any other signs of the illness. Many of the above mentioned symptoms will be present as well as others, such as confusion, dry cough, loss of appetite, mouth sores, nail changes, night sweats, personality changes, shortness of breath, tingling, numbness and weakness in limbs, thrush, and difficulty concentrating.

LATE STAGE SYMPTOMS:

During the *last stage* of HIV it progresses to AIDS. Symptoms of AIDS are

as previously mentioned in the *established stage symptoms*. During this stage it is easier to develop opportunistic infections such as pneumonia.

HOW IS HIV DIAGNOSED AND TREATED?

A medical doctor diagnoses HIV with blood tests (ELISA and Western Blot Assay blood tests). Because it takes up to six months after the original infection for antibodies to appear, it is important to repeat the tests six months after being exposed to the virus.

Treatment for HIV depends on the stage of the infection (early, established or late). If a person is in the early stages, one or two antiretroviral medications are recommended. If the patient is in a later or established stage, three or more antiretroviral medications are usually recommended.

If HIV is left untreated, AIDS often develops in most people within 12–13 years after first becoming infected. Young children or adults who rapidly progress through the stages of HIV may develop AIDS within 3 years. Left untreated, AIDS is often fatal within 18–24 months after developing it. To date, there is no cure for HIV/AIDS. Once HIV enters the body, the person has HIV for life.

HOW IS HIV/AIDS SPREAD?

- From an HIV positive mother to her baby during pregnancy, during birth, and through breastfeeding
- Through blood transfusions (although extremely rare)
- From occupational exposure in health care settings
- Through unprotected sex
- From non-sterile hypodermic needles (shared needles and syringes).

IS HIV/AIDS TRANSMITTED THROUGH CASUAL CONTACT?

The HIV/AIDS virus dies quickly when exposed to air. It cannot be

contracted from touching, kissing, coughing, sneezing, sharing drink glasses, doorknobs, toilet seats, swimming pools, sweat, tears, urine, feces, or through insect bites.

LIFE AT SCHOOL FOR CHILDREN WITH HIV/AIDS

A child with HIV should be allowed to attend school. School staff do not need to be informed that a child with HIV is attending the school. If it is necessary to inform school personnel of the child's HIV status, the information should be restricted to those officials who need to know. The child's right to privacy must be respected at all times. School staff and students are not at risk of becoming infected with the virus in the everyday social contact setting of a school environment. There is, however, potential for transmission when open skin sores or broken mucous membranes come in contact with body fluids or blood of a person with the virus.

SUPPORT FOR CHILDREN AND THEIR FAMILIES

Children who are HIV positive often have family members who are also HIV positive and suffer from socio-economic and psychological problems. Counseling and support for children and families can improve their quality of life, relieve suffering and help in the management of the illness. Support is also crucial for family members who are not HIV positive as they often care for and are responsible for sick parents or siblings.

AVAILABLE SUPPORT AND INFORMATION NETWORKS:

Oak Tree Clinic
B4 West 4500 Oak Street
Vancouver, B. C. V6H 3N1
www.oaktreeclinic.bc.ca

Health Canada *www.hc-sc.gc.ca/english/diseases/aids.html*

Canadian AIDS Society *www.cdnaids.ca*

Canadian HIV/AIDS Info Centre *www.clearinghouse.cpha.ca/*

CAAN (Canadian Aboriginal AIDS Network)
602-251 Bank Street
Ottawa, Ontario K2P 1X3
www.caan.ca

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Children with Special Needs In Early Childhood Settings: Identification, Intervention, Inclusion. Published by Pearson Education Inc. as Addison Wesley Publishing Co. 2004

Public Health Agency of Canada *www.phac-aspc.gc.ca/public/std-mts/sti_0.html* (February 14, 2003) *www.phac-aspc.gc.ca//aids-sida/hiv_aids/federal_initiative/care_treat/guide.html* (January 14, 2005)

B. C. Health Guide *www.bchealthguide.org* (June 18, 2004)

HIV/AIDS and Children *www.avert.org/children.htm* (March 22, 2005)

Oak Tree Clinic *www.oaktreeclinic.bc.ca · www.oaktreeclinic.bc.ca/oaktree/mission.asp*

Health Canada *www.hc-sc.gc.ca/english/iyh/diseases/hiv* (July 12, 2004)

B.C. Ministry of Education: Special Education Manual, Information Circular #412 (September 30, 2004)

A Manual of Policies, Procedures and Guidelines
HIV Infections, Ministry of Health Guides for the Management of Persons in Educational Settings, Risks Associated with School/Daycare Attendance
—Recommendations: *www.bced.gov.bc.ca/specialed/ppandg/appendix_e.htm*

Living with HIV—Teens Speak Out, Joanne, age 14 (no date)
www.channel4.com/health

Section 5G

Various Health Concerns

Bee-Sting Allergy

In most children, bee stings are not a major concern; however for the few who are allergic, a sting can be a serious, and possibly life-threatening ordeal. If a child has had an episode of extreme reaction to a sting, they should be tested for an allergy. If the test is positive, the doctor will recommend that a bee-sting kit be available to the child or caretaker at all times. The kit should include a prepared hypodermic dose of epinephrine and caretakers must read the instructions on how to administer the drug. As well, every adult in the school must be aware of the child's allergy and of the necessary steps to take in case of emergency.

SIGNS AND SYMPTOMS

SYMPTOMS OF AN ALLERGIC REACTION INCLUDE:

- Facial swelling
- Difficulty breathing
- Abdominal pain
- Shock
- Swelling of the lips or throat
- Faintness
- Dizziness
- Confusion
- Hives
- Rapid heartbeat
- Nausea, cramps, and vomiting

TREATMENT

If a child with a known allergy is stung and presents the listed symptoms, immediately contact emergency medical services and do the following while waiting for the ambulance to arrive:

- Retrieve the bee-sting kit and administer the epinephrine according to the package directives
- Have the child take an antihistamine pill after the epinephrine if they are able to do so without choking
- Have the child lie down with their feet elevated above their head
- Loosen tight clothing and cover them with a blanket
- Turn the child on their side if they begin to vomit or bleed from the mouth
- Begin CPR if there are no signs of circulation and you are qualified to do so

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REFERENCES

http://www.mayoclinic.com/health/first-aid-insect-bites/FA00046
http://www.medicinenet.com/insect_sting_allergies/article.htm

Cystic Fibrosis

Cystic fibrosis (CF) is a multi organ disease that affects primarily the lungs and digestive system. It is the most common, fatal genetic disease affecting young Canadians.

CAUSES

People are born with cystic fibrosis. It is a genetic disorder. Approximately one in every 25 Canadians carries a defective version of the gene responsible for CF and in most cases, they are not aware that they are carriers because they do not have CF.

When two people who carry a defective version of the gene responsible for CF have a child, there is a:

- 25% chance that the child will be born with cystic fibrosis
- 50% chance that the child will not have CF, but will be a carrier
- 25% chance that the child will not have CF, and will not be a carrier

With each pregnancy, the risks are exactly the same. Two carrier parents may have several children with CF or none at all.

HOW IS CF DIAGNOSED

Through genetic and prenatal genetic testing or a sweat test which measures the amount of salt in a person's sweat. A high salt level, along with other symptoms, points to the presence of cystic fibrosis.

CHARACTERISTICS OF CYSTIC FIBROSIS

Cystic fibrosis disturbs the functioning of the exocrine (outward secreting)

glands. Because of the abnormal functioning of these glands, breathing, digestion, and sweat production are affected.

Mucus produced by the exocrine glands in the lungs is normally thick slippery and clear. With CF this mucus is thick and sticky. It clogs breathing passages, and must be cleared away to prevent lung damage. The child with CF must undergo daily treatment routines to control the accumulation of this harmful mucus.

Without treatment, a child with CF cannot properly digest food—fortunately, this can be helped by taking supplementary enzymes and following a generous high calorie diet.

The sweat of persons with CF is high in salt. Consequently, children who are affected can lose a great deal of body salt through perspiration, and salt crystals may actually form on their skin.

HANDLING THE STUDENT IN SCHOOL

Children with CF do not appear to be sick, and may look very healthy. For this reason it is easy to forget that they have a potentially fatal disease, and there are precautions that must be taken to ensure their continued survival.

The student with cystic fibrosis has been taught how to handle the mucus build-up in his lungs. One of the strategies is that he must cough frequently. He must not be discouraged from doing so, nor given cough suppressants.

The student has also been taught to clear his throat into a tissue. Therefore, it will be helpful if the teacher makes sure there is a box of tissues and a means of disposal nearby. You can make your student feel more comfortable by making it easy for him to leave the classroom when necessary.

Physical activity helps the child to clear the mucus, and should be encouraged; however, the CF may limit the extent to which he can participate in strenuous activity.

Your student may need to take food supplements, antibiotics, or salt tablets. Some children feel embarrassed about taking pills in front of classmates, and may try to avoid taking them. Remember that these medications are vital to his health. You may want to keep the pills in your desk or in the nurse's office so that you can ensure that he takes them at the proper times.

As he gets older, it is important that the child learns to take responsibility for his own health care.

As with all children, group acceptance is very important. It may be hard for him to adjust to group situations, because the disorder tends to make him feel different. You can help to strengthen the child's self esteem and stimulate valuable relationships with other children by helping him gain acceptance in the classroom.

Paying undue attention to the medical needs of the child can be very embarrassing for the individual. Classmates should be taught that what he has is not contagious, and that the coughing, throat-clearing and medications are necessary parts of his routine.

If the teacher accepts these routines as normal, the members of the class will soon learn to accept them, too.

THE FUTURE

It wasn't too many years ago that most children with cystic fibrosis did not reach school age. Today, thanks to advances in treatment and research, half of all Canadians with CF are expected to live into their late-thirties and beyond. Young men and women with this disorder are entering colleges or universities, and seeking employment.

The rapid pace of research suggests that new therapies for cystic fibrosis may be available in the foreseeable future. Heart and lung transplants are being successfully performed for young adults whose organs have been badly damaged by the disorder. ~

For Further information contact the Canadian Cystic Fibrosis Foundation at 604 436 1158 or email *administrator@cfvancouver.ca*, or check out their website at *www.ccff.ca*

REFERENCES

www.ccff

Previous publication of *Putting the Puzzle Together*

Communication Disorders

The term *communication disorder* encompasses a wide variety of problems in language, speech, and hearing. Speech and language impairments include *articulation* problems, *voice* disorders, *fluency* problems (such as stuttering), *aphasia* (difficulty using words, usually as a result of a brain injury), *delays in speech and/or language*. Speech and language delays may be due to many factors, including environmental factors or hearing loss.

HEARING IMPAIRMENTS

Hearing impairments include *partial hearing* and deafness. Deafness may be defined as a loss sufficient to make auditory communication difficult or impossible without amplification. There are four types of hearing loss:

- *Conductive* hearing losses are caused by diseases or obstructions in the outer or middle ear and can usually be helped with a hearing aid.
- *Sensorineural* losses result from damage to the sensory hair cells of the inner ear or the nerves that supply it and may not respond to the use of a hearing aid.
- *Mixed* hearing losses are those in which the problem occurs both in the outer or middle ear and in the inner ear.
- A *central* hearing loss results from damage to the nerves or brain.

A child with a possible hearing problem may appear to strain to hear, ask to have questions repeated before giving the right answer, demonstrate speech inaccuracies (especially dropping the beginnings and endings of words), or exhibit confusion during discussion. Detection and diagnosis of hearing impairment have become very sophisticated. It is possible to detect the presence of hearing loss and evaluate its severity in a newborn child.

Many communication disorders result from other conditions such as learning disabilities, cerebral palsy, mental retardation, cleft lip or cleft palate.

CHARACTERISTICS OF CHILDREN WITH COMMUNICATION DISORDERS

A child with speech or language delays may present a variety of characteristics including the inability to follow directions, slow and incomprehensible speech, and pronounced difficulties in *syntax* and *articulation*. Syntax refers to the order of words in a sentence, and articulation refers to the manner in which sounds are formed. Articulation disorders are characterized by the substitution of one sound for another or the omission or distortion of certain sounds.

Stuttering

Stuttering or dysfluency is a disorder of speech flow that most often appears between the ages of 3 and 4 years and may progress from a sporadic to a chronic problem. Stuttering may spontaneously disappear by early adolescence, but speech and language therapy should be considered.

Voice Disorders

Typical voice disorders include hoarseness, breathiness, or sudden breaks in loudness or pitch. Voice disorders are frequently combined with other speech problems to form a complex communication disorder.

EDUCATIONAL IMPLICATIONS

Many speech problems are developmental rather than physiological, and as such they respond to remedial instruction. Language experiences are central to a young child's development. In the past, children with communication disorders were routinely removed from regular class for individual speech and language therapy. This is still the case in severe instances, but the

trend is toward keeping the children in the mainstream as much as possible. In order to accomplish this goal, teamwork among the teacher, speech and language therapist, audiologist, and parents is essential. Speech improvement and correction are blended into the regular classroom curriculum and the child's natural environment.

Amplification may be extremely valuable for the child with a hearing impairment. Students whose hearing is not completely restored by hearing aids or other means of amplification have unique communication needs. Children who are deaf are not automatically exposed to the enormous amounts of language stimulation experienced by hearing children in their early years. For deaf children, early, consistent and conscious use of visible communication modes such as sign language, finger spelling, and cued speech and/or amplification and aural/oral training can help reduce this language delay. Some educators advocate a strict oral approach in which the child is required to use as much speech as possible, while others favor the use of sign language and finger spelling combined with speech, an approach known as *total communication*. There is increasing consensus that whatever system works best for the individual should be used.

IN THE CLASSROOM

Many children with hearing impairments can be served in the regular classroom with support services. In addition to amplification, instructional aids such as captioned films and high interest/low vocabulary reading materials are helpful. For most children with hearing impairments, language acquisition and development are significantly delayed, sometimes leading to an erroneously low estimate of intelligence. Students whose physical problems are so severe that they interfere with or completely inhibit communication can frequently take advantage of technological advances that allow the individual to make his or her needs and wants known, perhaps for the first time.

—Adapted from *ERIC Digest* #E470. ERIC Clearing House, from previous publication of *Putting the Puzzle Together*

Depressive Illness

Suicide is a permanent solution to a temporary problem. There are other ways.

—DR. DAVID HORGAN

According to the Adolescent Health Survey, carried out in 2003 by the McCreary Centre Society of Vancouver, there has been a steady increase in suicide among youth over the past 25 years. It is now among the leading causes of death for adolescents. In 2003, 16% of students report seriously thinking about suicide, 22% planned a suicide and 7% said they attempted suicide.

DISTRESS

Results from the survey showed that females are consistently more likely to feel distressed than males. Feeling emotionally distressed seems to increase with age. This is consistent for both males and females. Those who had been physically abused were approximately three times more likely to report being seriously distressed and 2.5 times more likely if they had been sexually abused.

PROTECTIVE FACTORS

Survey results confirmed that strong connections to family and school have a positive impact on youth health with those youth feeling connected to either their family or school 99 and 98% less likely to attempt suicide than their peers who didn't feel connected.

SEEKING HELP

It was found that about half (49%) of youth asked a professional for help with a personal problem and that young people are most likely to seek help from school staff compared with other professionals. This offers school staff a unique opportunity to make a positive impact on a student's emotional health.

DEPRESSIVE ILLNESS

Depressive illness is a severe and prolonged condition with persistent sadness, negativity and difficulty coping being it hallmarks. The condition is painful and disabling, but has a very high cure rate.

DEPRESSIVE ILLNESS VERSES EVERYDAY DEPRESSION

Both conditions are brought on by stress or things going wrong; however, depressive illness involves a chemical change taking over your mind. This chemical change blocks out any positive or any possible solutions to your problems, and instead makes you see only negatives in everything around you and in yourself. It convinces you there is no hope of things getting better and every minor problem seems in its own way a major disaster.

CAUSES

For most, depressive illness results from a build-up of stress, which eventually cause a breakdown in internal chemistry.

All of the below factors, when stress is present, can increase the risk of developing depressive illness: Early, intensive and occasionally prolonged treatment, by a professional, gives the best chance of total recovery.

- Not communicating
- Multiple demands on a person's time
- Very little time to relax
- Certain personality characteristic:
  - being anxious or a worrier
  - lack of self confidence
  - difficulty in being assertive or expressing an opinion
  - perfectionism
- Having a fragile biochemistry
- Drinking excessive alcohol
- Smoking a lot of marijuana

RECOGNIZING A STUDENT WHO IS SUICIDAL

Suicidal ideas, threats, and attempts often precede a suicide. The most commonly cited warnings of potential suicide include:

- Extreme changes in behavior
- A previous suicide attempt
- A suicidal threat or statement
- Signs of depression

SIGNS OF DEPRESSION

Young children who have depression may have physical complaints, be agitated, or hear imaginary voices.

Adolescents may have school difficulties, may withdraw from social activities, have negative or antisocial behavior, or may use alcohol or other drugs. They may display increased emotionality, and their moods may be restless, grouchy, aggressive, or sulky. They may not pay attention to their personal appearance. They may refuse to cooperate in family ventures or want to leave

home. They may feel that they are not understood or that they are not approved of. They may be very sensitive to rejection in love relationships.

IN THE CLASSROOM

The primary role of all school personnel is to detect the signs of depression and potential suicide, to make immediate referrals to the contact person within the school, to notify parents, to secure assistance from school and community resources, and to assist as members of the support team in follow-up activity after a suicide threat or attempt. Discussions with student should stress the individuals and agencies that are available to help students and the steps they can take in seeking help for themselves, their friends, and their families in case of emergencies. ~

REFERENCES

BC Adolescent Health Survey fact sheet *www.mcs.bc.ca*

www.suicideprevention.com.au/lev1/depression-description.html · ERIC Digest #E508

Developmental Disability

A developmental disability is a condition which makes it more difficult for the individual to learn the same things as other children of the same age. In the past, these children were categorized as either *trainable* or *educable*, and placed in special classes or even special schools. We now know that many of these children can be taught basic skills, and even those with severe limitations can benefit from being in the regular classroom for at least part of the day.

Intellectual function is measured by the intelligence test, with a score of below 70 on such tests being regarded as having a developmental disability. Adaptive behaviour refers to a person's adjustment to everyday life. Difficulties may occur in learning, communication, social, academic, vocational, and independent living skills.

The greatest single factor causing a developmental disability is chromosomal abnormality. Down Syndrome and Fragile X Syndrome are the most common of these disorders. Other congenital causes include a lack of oxygen, blood incompatibilities between mother and fetus, maternal infections, and drug or alcohol use during pregnancy. After birth, a developmental disability can be a result of lead poisoning, diseases such as encephalitis or meningitis, brain damage caused by malnutrition, oxygen deprivation, convulsion or traumatic injury.

EDUCATION

People with a developmental disability have the capacity to learn, to develop, and to grow. The great majority of these citizens can become productive and full participants in society. Appropriate educational services that begin in infancy and continue throughout the developmental period and beyond

will enable children with a developmental disability to develop to their fullest potential. As with all education, modifying instruction to meet individual needs is the starting point for successful learning. Throughout their child's education, parents should be an integral part of the planning and teaching team.

TEACHING TIPS

- Use concrete materials that are interesting, age appropriate, and relevant to the students
- Present information and instructions in small, sequential steps and review each step frequently
- Provide prompt and consistent feedback
- Teach these children, whenever possible, in the same school they would attend if they did not have disabilities
- Teach tasks or skills that students use frequently, in such a way that students can apply the tasks or skills in settings outside of school
- Remember that tasks that many people learn without instruction may need to be structured, or broken down into small steps or segments, with each step being carefully taught

Children and adults with developmental disabilities need the same basic services that all people need for normal development: education, vocational preparation, health services, recreational opportunities, etc. In addition, many persons with developmental disablities need specialized services for special needs: diagnostic and evaluation centres, special early education opportunities, (beginning with infant stimulation programs and continuing through preschool) and educational programs that includes age appropriate activities, functional academics, transition training, and opportunities for independent living and competitive employment to the maximum extent possible.

RESOURCES:

SMITH, R. (Ed.). (1993). *Children with Mental Retardation: A Parents' Guide*. ROCKVILLE, MD: Woodbine House.

TRAINER, M. (1991). *Differences in Common: Straight Talk on Mental Retardation, Down Syndrome, and Life*. *Rockville*, MD: Woodbine House.

Hemophilia

Hemophilia is a hereditary disorder in which one of the plasma proteins needed to form a clot is missing or reduced. When a person with hemophilia is injured, he does not bleed harder or faster than normal, but will have prolonged bleeding because he cannot make a firm clot. Small cuts on the skin are usually not a problem, but bleeding in any deeper area can be prolonged. Some bleeding episodes occur as a result of injury, but many occur seemingly without cause. Apart from the absence of this one protein, the child with hemophilia is normal in every other way.

The severity of hemophilia differs among individuals. In mild hemophilia, bleeding is usually only a problem after major trauma or surgery. Children with moderate hemophilia may experience occasional bleeding without apparent cause. These are called spontaneous bleeding episodes.

CAUSES

Hemophilia is a sex-linked hereditary bleeding disorder transmitted on a gene of the X chromosome. While females can be carriers, it is very rare for them to have the condition themselves. Approximately 1 in 10,000 males is born with hemophilia. All races and socio-economic groups are affected equally.

TREATMENT

Small cuts and abrasions are treated the same as for any child by applying pressure and then a bandage. For under the skin bleeding apply an ice pack.

Other treatment depends on the severity of the hemophilia. Doctors of those with mild hemophilia A will mostly likely administer desmopressin

(a drug stimulating more of your own clotting factor) intravenously to stop the bleeding. Occasionally, desmopressin is given through a nasal route.

For moderate to severe *hemophilia A* and *hemophilia B*, more serious treatment is in order. The body cannot provide nearly enough clotting factor and thus requires a doctor to administer recombinant clotting factors (clotting factors derived from human blood or synthetic products) intravenously. In some cases doctors recommend preventative injections to avoid bleeding episodes.

For the most severe form, *hemophilia C*, plasma infusions are given to prevent bleeding episodes from occurring.

PROMPT TREATMENT IS IMPORTANT

Prompt, adequate treatment of bleeding enables rapid recovery, and prevents resultant arthritis and deformity. If the child bleeds into a joint and receives clotting factor promptly, the bleeding ceases before a large quantity of blood escapes into the joint space. If treatment is delayed, more blood leaks into the joint causing pain and requiring a longer time for reabsorbtion; then a prolonged period of time is required before normal activities are possible.

If a bruise develops on the child's face or forehead, he should be taken to the hospital immediately. Ice should be used to decrease the size of the leaking blood vessels and limit the amount of bleeding into the tissues.

The school should keep a supply of ice bags available at all times. A wet towel, wrung out and frozen in a plastic bag, makes an effective ice treatment for joint or deep muscle bleeding.

SYMPTOMS OF BLEEDING

The first sign of bleeding *deep in a muscle* may be the child's reluctance to use the limb. Beware of a complaint of *pulled muscles*—they are often confused with deep muscle bleeding. A pulled muscle complaint is always considered a deep muscle bleeding unless proven otherwise.

A bleeding episode in a muscle can spread through the muscle length, often without your noticing it. When muscle bleeding occurs in the *forearm*, *calf*, or *groin*, swelling can create pressure on the nerves which can result in numbness, and subsequent pain and inability to move the limb.

Early signs of bleeding into the joint are the child's reluctance to use the affected limb followed by a slight swelling in the affected joint. As more blood leaks into the joint it feels warmer than the opposite one and the swelling feels *spongy*. Later, the child will hold the limb in a bent or *flexed* position to ease the pain. If untreated, bleeding continues until the area feels hot and rock hard. Usually there is no bruising associated with a joint bleed, and since the bleeding occurs in an enclosed space and has nowhere to spread, the pressure caused by the bleeding eventually results in pain.

The first signs of *throat or neck* bleeding may be vomiting of swallowed blood. If there is no minor nose or mouth bleeding, the child should be taken to the hospital immediately. Throat and neck bleeding is considered serious because of the potential problem of blocked airways.

All *head injuries* are to be considered serious because of the potential danger of brain hemorrhage. Apply ice to prevent a small bruise from enlarging, and obtain medical treatment right away. Sometimes symptoms of brain hemorrhage can be delayed for several days. It can occur with no bruise on the scalp, which is why it is important for the doctor to examine the child. Minor problems associated with head injuries can be a nuisance. Sometimes a black-and-blue *goose-egg* develops on the forehead or scalp, and it is important to protect this lump from damage. This can be done by arranging *doughnut* padding around the lump.

Abdominal and *chest wall* injuries can be serious because of possible injury to internal organs. Injury may occur without sign of bruising, so any complaint of abdominal pain should be investigated by the doctor. Sometimes pain is delayed for several hours after the injury takes place. Injuries to the chest wall can be quite painful if bleeding occurs in the small muscles between the ribs. Bleeding in either the abdomen or chest requires investigation by the doctor.

WHAT ABOUT SPORTS AND P.E.?

Exercise is particularly important for the child with hemophilia. Strong muscles provide more protection for joints, and activity develops agility, coordination, and endurance.

Guidance and supervision are necessary for choosing appropriate activities. However, the child must learn through supervised trial and error which is good for him. If he experiences bleeds and pain from certain activities, he will probably abandon those activities and select others that are safer for him, yet still fun. Forbidding specific sports is usually futile.

The child with hemophilia should not attempt sports that require time and effort to develop skill—such as tennis, cross-country skiing, horseback riding, and skating- without proper training. Contact sports such as football, rugby, wrestling, and hockey should be discourages as well as skateboarding. Swimming, cycling, and walking are good activities as they create little stress on the joints.

Speak to the child's doctor, physical therapist, or nurse for assistance in setting up a physical education program for the child with hemophilia.

REMEMBER

The parents have already lived through many crises with this child. They are the experts on his particular needs and limitations.

REFERENCES

www.mayoclinic.com/health/hemophilia/DS00218/DSECTION=treatments-and-drugs

www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=180&contentid=45&rptname=bleeding

Muscular Dystrophy

Muscular dystrophy is a group of diseases in which muscle fibers are unusually susceptible to damage. The diseases are both hereditary and progressive.

The essential characteristics of muscular dystrophy appear to be the progressive breakdown and then death of muscle fibre. Gradually there is a loss of muscle bulk and increasing weakness, causing difficulty in activities such as walking and the use of the arms. Deterioration will continue slowly over a period of years. Breathing often becomes increasingly affected as the disease progresses.

There are many types of muscular dystrophy, with different ages of onset, different characteristics, and different rates of progression. The most common and most severe type is Duchenne muscular dystrophy.

WHAT CAUSES DUCHENNE'S MUSCULAR DYSTROPHY?

Duchenne muscular dystrophy (DMD) is a genetic disorder in which an abnormal gene is passed from mother to son, in this case on the X chromosome. Only males are affected, except in rare instances. Daughters of a carrier mother may also be carriers. Many carriers are unaware of a family history.

Many cases of DMD arise spontaneously as a result of a gene mutation in either the mother or the child. Over the past few years there has been much research, and there is progress being made in finding the causes and possible ways of treating this disease.

CHARACTERISTICS OF DMD

Boys with DMD appear normal at birth. Usually between the ages of two and six, parents notice clumsiness or frequent falling. Over the next few

years, as the disease progresses, the child will become more unsteady on their feet. A diagnosis is usually confirmed through medical investigation at this time.

As balance difficulties and weakness progresses, the child will become much slower in all activities. Braces are often prescribed at the time when he begins to toe-walk and fall frequently. Braces tend to increase the child's stability and extend the period of time that he will be able to continue to walk. Later, as the disease progresses, breathing is increasingly affected. Lifespan is shortened.

At some point it will be necessary for the child to begin using a wheelchair. Initially this will only be for long outings or over rough ground but gradually he will become more and more dependent on the wheelchair for mobility. When this happens, there is a need for the child to mourn this loss. There can be a painful period of awareness when the limitations imposed by the disorder are uppermost in the child's mind. Problems multiply; it becomes difficult for him to go very far on his own, or he falls often and cannot get up without assistance. He becomes depresses, anxious, and his activities often suffer. Instead of sharing his usual interests of persons his own age, he must focus on himself in order to evaluate his limits and try and ease his situation.

The transition to a wheelchair is initially very upsetting, but carries with it certain advantages. The child can cover much greater distances without excessive fatigue. Once the readjustments have been completed, the individual regains his interests and continues to progress.

Some children with DMD may be a little slower to learn than their peers, but the progress of the disease does not affect mental capacity.

IN THE CLASSROOM

There are many things that students and teachers can do to help a student with DMD cope. Having sensitivity to the person's self-image and self-esteem is probably the greatest guide to providing assistance.

Teachers, administrators, and other students rarely consider what it

would be like to live with the knowledge that they have a disease which means that at some point in the future, they will not be able to even walk or perform such simple tasks as buttoning their shirt.

TEACHING STRATEGIES

School is more than a place to acquire skills; it is a centre of interpersonal activities where an individual creates new ties outside the family. For those children who may not reach adulthood, school represents a major portion of their lives. It is inevitable that at certain times the child will ask why he should bother making an effort at school if his future is limited.

Not all children with neuromuscular disorders such as muscular dystrophy experience learning difficulties. A considerable number are of normal or superior intelligence. Low scholastic scores can simply be an indication that the child is tired or preoccupied with the progression of his disorder. These children have to cope with others expectations that may be too demanding or, conversely, too low. It is very important to find goals suitable for each child.

It is important to modify current teaching methods to avoid further handicapping those who can do well scholastically. For instance, children with DMD may need an alternative to written work. As well, it is important for the teacher to make sure the child feels welcome in the classroom and is not isolated by peers because of his physical differences.

PHYSICAL EDUCATION AND RECREATION

Limitations of each individual will be different, but the one thing that can be said is that progressive deterioration is ongoing. Many students do not want to participate in P.E. programs because it is so frustrating to them and can be a deflating experience. Try to structure situations so that the student can be a winner. Learn the student's physical abilities and look for alternatives.

Let him be a timekeeper or scorekeeper if he cannot participate as a player or competitor. If the student says he cannot do an exercise or activity, that should be respected. If the child feels strongly about not participating, it is usually best not to force him to take part. ~

REFERENCES:

http://www.mayoclinic.com/health/muscular-dystrophy/DS00200
http://www.mda.org/publications/tchrdmd/tips.html

Serious Medical Problems

Much as we hate to acknowledge it, there are children who have life-threatening medical disorders such as heart conditions, cancer, AIDS, and others.

While these illnesses may not affect the intellectual abilities of the child, they may make it difficult for him to keep pace with others in the class. Fatigue is the most common debilitator for all children with medical conditions—guidelines should be sought from the parents and doctor as to what accommodations need to be made for the individual.

BC Children's Hospital will have established a transition plan for any child under their care who has returned to the community. The implementation of this plan is entrusted to the Public Health team in the area. The P.H. nurse will undoubtedly contact the child's school to carry out this plan. If you have any concerns about a student who has been a patient at Children's Hospital, request assistance from the Public Health Team; failing this, contact the Community Liaison Department at Children's Hospital. Other hospitals, such as Queen Alexandra Health Care for Children, in Victoria, and the Regional Hospital in Prince George, will also be able to give you guidance about a child for whom they have cared.

How much to tell the other students about a child's illness is always a sensitive issue. Again, seek guidance from the parents and the Public Health Team. Students can be amazingly supportive of their classmate if they are given the opportunity—as in a whole class having their heads shaved to make one of their number feel more comfortable when returning from a session of cancer treatment which has caused a loss of hair!

If a student must leave school for a period of treatment in hospital, encourage the others in the class to maintain contact, through letters, cards, audio or video-tapes. Keep the class informed as to how their classmate is progressing, and what changes to expect when he/she returns to school.

Section
6

Support Groups & Organizations

Adult Learning Disabilities Association
Suite 608–409 Granville Street,
Vancouver, BC V6C 1T2
Phone: 604 683 5554
Fax: 604 683 2380
enquiry@alda-bc.org
www.alda-bc.org

AIDS Vancouver
1107 Seymour Street
Vancouver, BC V6B 5S8
Phone: 604 893 2201
Fax: 604 893 2205
contact@aidsvancouver.org
www.aidsvancouver.org

Allergy and Asthma Information Association
303–1212 West Broadway
Vanouver, BC V6H 3V1
Phone: 604 731 9884
www.aaia.ca

Arthritis Society of BC
#200–1645 West 7th Avenue
Vancouver, BC V6J 1S4
Phone: 604 714 5550
Toll Free: 1 866 414 7766
Fax: 604 714 5555
info@bc.arthritis.ca
www.arthritis.ca/bc

Autism Society of BC
#303–3701 East Hastings Street
Burnaby, BC V5C 2H6
Phone: 604 434 0880
Toll Free: 1 888 437 0880
Fax: 604 434 0801
www.autismbc.ca

BC Association for Community Living
BCACL is a federation working with partners to build community and to enhance the lives of children, youth and adults with developmental disabilities and their families by supporting abilities, promoting action and advancing rights, responsibilities and social justice.

227 6th Street
New Westminster, BC V3L 3A5
Phone: 604 777 9100
Fax: 604 777 9394
info@bcacl.org
www.bcacl.org

BC Brain Injury Association
PO Box 2324
Chilliwack, BC V2R 1A7
Phone: 604 465 1783
Fax: 604 465 1725
Toll Free: 1 877 858 1788
www.bcBrainInjuryAssociation.com

BC's Children's Hospital
4480 Oak Street
Vancouver, BC V6H 3H1
Phone: 604 875 2345
Toll free in BC: 1 888 300 3088
www.bcchildrens.ca

BC Coalition for People with Disabilities
204–456 W. Broadway
Vancouver, BC V5Y 1R3
Phone: 604 875 0188
Toll Free: 1 800 663 1278
Fax: 604 875 9227
feedback@bccpd.bc.ca
www.bccpd.bc.ca

BC Council for the Family
The BC Council for Families works to build healthy families in a healthy society. We provide educational resources on parenting, childhood development, parent-teen relationships, work-life balance, suicide awareness and more. We support family education professionals by coordinating professional development workshops and symposiums, participating in conferences and disseminating research and resources.

#204–2590 Granville Street
Vancouver, BC V6H 3H1
Phone: 604 660 0675
Toll Free: 1 800 663 5638 (Canada/USA)
Fax: 604 732 4813
bccf@bccf.bc.ca
www.bccf.bc.ca

BC Epilepsy Society
Suite 510
999 West Broadway
Vancouver, BC V5Z 1K5
Phone: 604 875 6704
Fax: 604 875 0617
info@bcepilepsy.com

B.C. Federation of Foster Parent Associations
200–7342 Winston St.
Burnaby BC V5A 2H1
Phone: 604 664 0124
Fax: 604 664 0127
Toll Free in BC: 1 800 663 9999
bcffpa@istar.ca
www.bcfosterparents.ca

BC Lung Association
2675 Oak Street
Vancouver, BC V6H 2K2
Phone: 604 731 LUNG (5864)
Toll Free: 1 800 665 LUNG (5864)
Fax: 604 731 5810
info@bc.lung.ca
www.bc.lung.ca

BC Paraplegic Association
780 s.w. Marine Drive
Vancouver, BC V6P 5Y7
Phone: 604 324 3611
Fax: 604 326 1229
Toll Free: 1 877 324 3611
vancouver@bcpara.org
www.bcpara.org

BC Rehabilitation Foundation
4255 Laurel Street
Vancouver, BC V5Z 2G9
Phone: 604 737 6383
Fax: 604 737 6494
www.bcrehab.com

BC Schizophrenia Society
#201–6011 Westminster Hwy
Richmond, BC V7C 4V4
Phone: 604 270 7841
Toll Free: 1 888 888 0029
Fax: 604 270 9861
www.bcss.org

BC Special Olympics
#210–3701 East Hastings Street
Burnaby, BC V5C 2H6
Phone: 604 737 3078
Fax: 604 737 3080
Toll Free: 1 888 854 2276
info@specialolympics.bc.ca
www.specialolympics.bc.ca

BC Disability Sport
#217–12837 76 Avenue
Surrey, BC V3W 2V3
Phone: 604 598 7890
TTY: 604 598 7890
Fax: 605 598 7892
www.disabilitysport.org

Canadian Association of Occupational Therapists
CTTC Building, Suite 3400
1125 Colonel By Dr
Ottawa, ON K1S 5R1
Phone: 613 523 CAOT (2268)
Toll Free: 800 434 CAOT (2268)
www.caot.ca/

Canadian Association for Williams Syndrome
Provincial Contact
Cindy Sanford
Box 26206
Richmond, BC V6Y 3V3
Phone: 604 214 0132
cawbc@yahoo.com
caws.sasktelwebhosting.com/

Canadian Cancer Society—BC/Yukon Division
565 West 10th Ave.
Vancouver, BC V5Z 4J5
Phone: 604 872 4400
Toll Free: 1 800 663 2524
Fax: 604 872 4405
inquiries@bc.cancer.ca
www.cancer.ca

Canadian Council on Rehabilitation and Work
410–167 Lombard Ave.
Winnipeg, Manitoba R3B 0T6
1 800 526 2262
www.ccrw.org

Canadian Cystic Fibrosis Foundation—Vancouver and Lower Mainland
4050 Gravely Street
Burnaby BC V4C 4A5
Phone: 604 436 1158
Fax: 604 436 1154
cfvancouver.ca

Canadian Deaf-Blind and Rubelle Association—BC Chapter
713 Columbia St
New Westminster, BC V3M 1B2
Phone: 604 517 6174
Fax: 604 517 6137
bcinfo@cdbrabc.ca
www.cdbrabc.ca

Canadian Diabetes Association—Vancouver Chapter
360–1385 8th Avenue W
Vancouver, BC V6H 3V9
Phone: 604 732 1331
www.diabetes.ca

Canadian Down Syndrome Society
811 14 Street NW
Calgary, AB T2N 2A4
Toll Free: 1 800 883 5608
Fax: 403 270 8500
info@cdss.ca
www.cdss.ca

Canadian Hard of Hearing Association—BC Chapter
102–9300 Nowell St
Chilliwack BC V2P 4V7
Phone: 604 795 9238
Fax: 604 795 9628
www.fraservalleydir.com

Canadian Hemophilia Society—BC Chapter
PO BOX 21161
Maple Ridge Sq. RPO
Maple Ridge, BC V2X 1P7
Phone: 604 688 8186
chsbc@shaw.ca

Canadian Liver Foundation—BC/ Yukon Region
109–828 West 8th Avenue
Vancouver, BC V5Z 1E2
Phone: 604 707 6430
Toll Free: 1 800 856 7266
Fax: 604 681 6067
radmin@liver.ca
www.liver.ca

Canadian Mental Health Association, BC Division
Suite 1200–1111 Melville Street
Vancouver, BC V6E 3V6
Phone: 604 688 3234
Toll Free in BC: 1 800 555 8222
Fax: 604 688 3236
info@cmha.bc.ca
www.cmha.bc.ca

Canadian National Institute for the Blind—Vancouver Chapter
100–5055 Joyce Street
Vancouver, BC V5R 6B2
Phone: 604 431 2020
Fax: 604 431 2099
www.cnib.ca

Canadian Wheelchair Sports Association—BC Division
3820 Cessna Drive Suite 210
Richmond, BC V7B 0A2
Phone: 604 333 3539
Fax: 604 333 3450

Caregivers Association of BC
7731 Yukon Street
Vancouver, BC V5X 2Y4
Phone: 604 734 4812
info@caregiverbc.ca
www.caregiverbc.ca

Cerebral Palsy Association of British Columbia
801–409 Granville Street
Vancouver, BC V6C 1T2
Phone: 604 408 9484
Fax: 604 408 9489
Toll Free: 1 800 663 0004
info@bccerebralpalsy.com
www.bccerebralpalsy.com

War Amps of Canada
National Headquarters
2827 Riverside Drive
Ottawa, ON K1V 0C4
Toll Free: 1 800 465 2677
Fax: 613 731 3234
www.waramps.ca

Children and Adults with Attention Deficit Disorder—Vancouver
PO BOX 74670
Vancouver, BC V6K 4P4
Phone: 604 222 4043
www.vcn.bc.ca/chaddvan

College of Dieticians of BC
Suite 103–1765 West 8th Avenue
Vancouver, BC V6J 5C6
Phone: 604.736.2016
Toll Free in BC: 1 877 736 2016
Fax: 604.736.2018
info@collegeofdietitiansbc.org
www.collegeofdietitiansbc.org

Crane Resource Centre
The Crane Resource Centre and Library is the principal resource for people who are blind, visually impaired, or print-handicapped.

1874 East Mall
Vancouver, BC V6T 1Z1
Phone: 604 822 6111
www.library.ubc.ca/home/access/crane.html

Crohn's and Colitis Foundation of Canada—BC Chapter
Suite 327, 8–6014 Vedder Road
Chilliwack BC V2R 5P5
Phone: 604 794 7656
Toll free: 1 800 513 8202
Fax: 604 794 7666
www.ccfc.ca

Deaf Children's Society of BC
200–7355 Canada Way
Burnaby, BC V3N 4Z6
Phone: 604 525 6056
TTY: 604 525 9390
Fax: 604 525 7307
Toll Free: 1 877 525 6056
deafbc@deafchildren.bc.ca
www.deafchildren.bc.ca/

Dial-a-Dietician
Dial-A-Dietitian is a free nutrition information line for British Columbians. Our registered dietitians can provide brief nutrition consultation by phone. If you need more in-depth counselling, they will guide you to hospital outpatient dietitians, community nutritionists or other nutrition services in your community.

Phone: 604 732 9191
Toll Free: 1 800 667 3438
www.dialadietician.org

Dyslexia Canada
P.O. Box 33026
West Vancouver, B.C. V7V 1H0
Phone: 604 921 1084
Email: info@dyslexiacanada.com
www.dyslexiacanada.com

Dystonia Medical Research Foundation
8 King Street East, Suite 106
Toronto, ON M5C 1B5
Phone: 416 488 6974
Fax: 416 488 5878
800 361 8061 (English)
800 787 1015 (French)
Email: info@dystoniacanada.org
www.dystonia-foundation.org

Eating Disorder Resource Centre of BC
c/o St. Paul's Hospital
1081 Burrard Street
Vancouver, BC V6Z 1K7
Phone: 604 631 5313

Employment Program for Persons with Disabilities
Employment Program for Persons with Disabilities (EPPD) provides a range of specialized services to help individuals with disabilities participate in their communities; pursue their employment goals as they are able, increase their self-reliance, and build skills and experience that may lead to further employment or volunteer opportunities. It is intended to assist persons with disabilities to achieve their economic and social potential to the fullest extent possible.

Contact your Ministry of Human Resources.

In Victoria call: 250 387 6121
In Vancouver call: 604 660 2421
Elsewhere in BC call: 1 800 663 7867
Outside British Columbia:
604 660 2421
EnquiryBC@gov.bc.ca

Fetal Alcohol Disorders Society
2448 Hamilton Road,
Bright's Grove, ON N0N 1C0
Phone: 519 869 8026
info@faslink.org
www.faslink.org

The Family Support Institute
227 6th Street
New Westminster, BC V3L 3A5
Phone: 604 540 8374
Toll free: 1 800 441 5403
Fax: 604 540 9374
www.familysupportbc.com

Gateway Society Services for Persons with Autism
4807 Georgia Street
Delta, BC V4K 2T1
Phone: 604 946 0401
Fax: 604 946 8429
www.gatewaysociety.org

IAM CARES Society
IAM CARES SOCIETY is a charitable, non-profit organization. We offer a full range of free employment assistance and support services to people with all types of disabilities and/or chronic conditions who live in the Lower Mainland and Greater Vancouver regions of British Columbia.

Suite 102–5623 Imperial Street
Burnaby, BC V5J 1G1
Phone: 604 436 2921
Fax: 604 436 9100
TTY: 604 436 2924
www.iamcares.com

Information Children
Information Children is a non-profit organization in existence since 1979. We provide information, support and referrals to parents and anyone involved in the care of children.

AQ 6198 Simon Fraser University
Burnaby, BC V5A 1S6
778 782 3548
Fax: 778 782 5846
Email infochld@sfu.ca
www.sfu.ca/infochild

Juvenile Diabetes Research Foundation—Vancouver Chapter
6450 Roberts St. Suite 150
Burnaby, BC V5G 4E1
Phone: 604 320 1937
Toll Free: 1 877 320 1933
Fax: : 604 320 1938
vncr@jdrf.ca
www.jdrf.ca

Kidney Foundation of Canada —BC Division
200–4940 Canada Way
Burnaby BC V5G 4K6
Phone: 604 736 9775
Toll Free in BC: 1 800 567 8112
Fax: 604 736 9703
info@kidney.bc.ca
www.kidney.bc.ca

Kids on the Block
Kids on the Block uses the power of puppetry to inspire children to appreciate differences, say no to all forms of prejudice, and develop skills to grow up healthy and safe.
(contact through the BC Coalition of People with Disabilities)

Kinsmen Rehabilitation Foundation of BC
300–999 West Broadway
Vancouver, BC V5Z 4R1
Phone: 604 736 8841

Learning Disabilities Association of Vancouver
3292 E Broadway,
Vancouver, BC V5M 1Z8
Phone: 604 873 8139
Fax: 604 873 8140
info@ldav.ca
www.ldav.ca

Lions Society of BC—Vancouver
The Lions Society provides services for youth and children with physical and or developmental disabilities, including patient care, and help with education and personal development. They operate Easter Seal Houses in Vancouver, Victoria, and Prince George as well as operating Easter Seal Camps at Squamish, Winfield, and Shawnigan year-round.

3981 Oak Street
Vancouver, BC V6H 4H5
Phone: 604 873 1865
Fax: 604 873 0166
Toll Free: 1 800 818 4483
info@lionsbc.ca

Ministry for Children and Families
In Victoria call 387 6121
In Vancouver call 604 660 2421
Elsewhere in B.C. call 1 800 663 7867
Outside B.C. call 604 660 2421
EnquiryBC@gov.bc.ca
www.gov.bc.ca/mcf

Mood Disorders Association of BC
202–2250 Commercial Drive
Vancouver, BC V5N 5P9
Phone: 604 873 0103
Fax: 604 873 3095
info@mdabc.net
www.mdabc.net

Muscular Dystrophy Association of Canada—Vancouver Chapter
7th Floor, 1401 West Broadway
Vancouver, BC V6H 1H6
Phone: 604 732 8799
Fax: 604 731 6127
Toll Free: 1 800 366 8166
infowest@muscle.ca
www.muscle.ca

The National Eating Disorders Information Centre
ES 7–421, 200 Elizabeth Street
Toronto, ON M5G 2C4
1 416 340 4156
Fax: 1 416 340 4736
Toll Free: 1 866 633 4220
nedic@uhn.on.ca
www.nedic.ca

Neil Squire Foundation
The Creative Employment Options Program assists people with physical disabilities in developing the necessary skills to establish themselves in employment positions.

Suite 220–2250 Boundary Road
Burnaby, BC V5M 3Z3
Phone: 604 473 9363
Fax: 604 473 9364
info@neilsquire.ca
www.neilsquire.ca

North Shore Employment Assistance Program
This program assists people with disabilities and/or chronic health conditions prepare for, obtain, and keep employment, or become self-employed. Services include: needs assessment, case management, career planning, help accessing educational funding, job search skill training, access to the internet, direct employer contacts, and referrals to job leads. Also coordinates wage subsidies for employers who choose to hire a person with a disability and/or chronic health condition.

303–935 Marine Drive
North Vancouver, BC V7P 1S3

Open Learning Agency
At Thompson Rivers University
Kamloops, BC
www.ola.bc.ca

Pacific Assistance Dogs Society (PADS)
PADS provides specially trained assistive animals to aid personal independence—opening doors or retrieving fallen objects etc.

9048 Stormont Ave
Burnaby, BC V3N 4G6
Phone: 604 527 0556
Fax: 604 527 0558
info@pads.ca
www.pads.ca

Pacific Association for Autistic Citizens
201–3277 Cambie Street
Vancouver, BC V5Z 2W3
Phone: 604 879 8888

Pacific Children's Heart Network
BC's Children's Hospital Social Services Dept.
4480 Oak Street
Vancouver, BC V6H 3V4
Phone: 604 875 3474

Pearson Computer Centre
700 West 57th Ave.
Vancouver, BC V6P 1S1
Phone: 604 327 3795

BC Prader-Willi Syndrome Association
2129 Lillooet Cr.
Kelowna, BC V1V 1W3
www.bcpwsa.com

Queen Alexandra Centre for Children
With historic roots originating over 80 years ago, the Foundation continues to provide financial assistance for programs, equipment and services that support the health and well-being of children, youth and families on Vancouver Island and the Gulf Islands.

2400 Arbutus Road
Victoria BC V8N 1V7
250 721 6723
Fax: 250 721 6715
info@queenalexandra.org
www.queenalexandra.org

Rett Syndrome Association
7531 Malahat Drive
Richmond BC V7A 4H1
Phone: 604 275 2722

The Society for the Children and Youth of BC
Since 1974, SCY has provided a forum for multi-disciplinary exchange and action for organizations and individuals working with and for young people. SCY actively involves volunteers from fields such as law, health, education, child development, social services, urban design and planning, recreation and business.

306–1212 West Broadway
Vancouver, BC V6H 3V1
Phone: 604 433 4180
info@scyofbc.org
www.scyofbc.org

The Society of Special Needs Adoptive Parents—BC
445–5525 West Boulevard
Vancouver, BC V6M 3W6
Phone: 604 687 3114
Fax: 604 687 3364
info@snap.bc.ca
www.snap.bc.ca

Special Education Technology—BC
105–1750 West 75th Avenue
Vancouver, BC V6P 6G2
Phone: 604 261 9450
Fax: 604 261 2256
www.setbc.org

Spina Bifida & Hydrocephalus Association of BC
4480 Oak Street
Vancouver, BC V6H 3V4
Phone: 604 878 7000
Fax: 604 677 6608
info@sbhabc.org

Sunny Hill Health Centre for Children
3644 Slocan Street
Vancouver, BC V5M 3E8
Phone: 604 453 8300
Fax: 604 453 8301
www.bcchildrens.ca

Support Organization for Trisomy 13 & 18
2376 Maple Street
Vancouver, BC V6J 3T4
Phone: 604 732 4248

TASH (The Association for Persons with Severe Handicaps)
101–1001 West Broadway Box 128
Vancouver, BC V6H 4B1
Phone: 604 873 9956
www.tash.org

Technology for Independent Living (TIL) Program
9007 Shaughnessy Street
Vancouver, BC V6P 6R9
Phone: 604 326 0175
Fax: 604 326 0176
til@bcits.org
www.tilbcits.org

Tetra Development Society
This society recruits skilled volunteer engineers, health professionals, and technicians to work one-on-one with people who have physical disabilities to create customized assistive devices that help achieve greater independence and integration into the community.

Suite 207–3077 Granville Street
Vancouver, BC V6H 3J9
Phone: 604 688 6464
Toll Free: 1 877 688 8762
Fax: 604 688 6463
info@tetrasociety.org
www.tetrasociety.org

Tourette Syndrome Foundation of Canada
984 West Broadway
Box J3556
Vancouver, BC V5Z 4M6
Phone/Fax: 604 732 3594
www.tourette.ca

Vancouver Resource Society
This society provides information and referral services for people who have physical disabilities. They promote community independent living and operate group homes for children and adults.

#310–2006 West 10th Ave
Vancouver, BC V6J 2B3
Phone: 604 731 1020
Fax: 604 731 4003
vanres@vrs.org
www.vrs.org

Western Institute for the Deaf and Hard of Hearing
2125 West 7th Ave
Vancouver, BC V6K 1X9
Phone: 604 736 7391
TTY (TDD): 604 736 2527
info@widhh.com
www.widhh.com

Youth Bridges to the Future
YBF assists those with disabilities (15–24 years of age) to achieve community integration and participation and attain realistic educational, employment, and life skills training.

7th Floor–1401 West Broadway
Vancouver, BC V6H 1H6
Phone: 604 742 2156
www.bridgestothefuture.ca