



Dual

Diagnosis

A Guide for Families of a Child with an
Intellectual/Developmental Disability and a Mental Disorder

Developed in partnership with The FORCE Society for Kids' Mental Health and the Family Support Institute

The F.O.R.C.E.
Families Organized for Recognition and Care Equality
Society for Kid's Mental Health



Please feel free to print or photocopy this resource, provided the content is not altered and The FORCE Society for Kids' Mental Health and the Family Support Institute are acknowledged.

The information in this guide is not intended to provide professional advice, for which the user is encouraged to seek the services of a qualified professional.

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Introduction

When a child is born, as parents we are full of hope for our newborn child. There is no greater joy than to be a part of each stage of development that your child goes through. As parents, we are prepared for the happy and hard times of raising our children. Yet there are times when being a parent can be very difficult.

When you have a child with special needs whose life is further complicated with a mental disorder, things may become very difficult for you and your family. As parents ourselves, we recognize that these are very hard times.

Many of us have walked the walk you are on and realize the very difficult life you may be living at this time. We have created this resource containing stories from a family member, and from a youth who has been given the label of a dual diagnosis, along with summaries of information drawn out of the stories that we think will be helpful to you. We have also included a list of things you can ask people to help you with, and a small dictionary of terms you will hear along the way.

We know that when you have a child who has been given this diagnosis you may find yourself winding your way through this maze of services for your child. It can be very confusing and exhausting. It is our hope that some of what we have experienced and learned may help you get through today, this week, and on into the future. We hope that you will find information and ideas here that will make things a little easier for you.

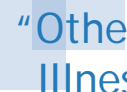
Even though it may seem hopeless right now, there is a light at the end of the tunnel, and our hope is that one day your family will feel calm again.

Our most important message is: "Don't ever feel you have to go it alone." There are people out there—family, friends and trusted professionals—who are willing to be there to support you and help you through this journey. When you feel alone, never feel afraid to pick up the phone and contact us:

- Family Support Institute - www.familysupportbc.com - 604-875-1119 ext. 523 or 1-800-441-5403
- The FORCE Society for Kids Mental Health - www.bckidsmentalhealth.org - 1-800-661-2121

If it is an emergency, call the Distress Line at 1-800-784-2433, Kids Help Phone at 1-800-688-6868, or call 911.

We are here to listen and try to make your journey easier.



"Others have holidays.
Illness doesn't take a
vacation or a holiday."

Denise's Story | Dual Diagnosis from a Parent's Point of View

This short story highlights a few years of my family's journey navigating the seas of developmental disability and mental health challenges—also known as dual diagnosis. We have weathered many storms as a family and have finally come to a place where life is wonderful!

I have never been comfortable describing my daughter by label or diagnosis. She isn't a diagnosis; she is a young woman! However, for the purposes of this resource, I have shared our story using the language of reports and assessments.

My beautiful blonde daughter, Denise, is now 22 years old and has grown into a vibrant young woman. She doesn't communicate with speech, but interacts using sounds, photos and gestures.

Denise was first diagnosed with “infantile autism” when she was less than a year old and assessed as “severely mentally handicapped” by the time she started kindergarten.

What were the first signs of mental health challenges?

Denise always had periods of time when she cried inconsolably. She had a difficult time when she was teething and when she experienced physical discomfort. Over the years, she also found some things difficult, like waiting for something or not getting what she wanted when she wanted it. These circumstances could trigger screaming and hand biting.

When Denise was about 16 years old, it seemed that her behaviour was becoming more and more challenging. At first, I wasn't sure whether I was just getting more tired, or if she was really having a more difficult time than in the earlier years. She had grown physically and it was becoming more challenging to re-direct her from harming herself. Things reached a point where Denise's behaviour no longer seemed to be triggered by anything going on around her. She could be listening to music in her room, and all of the sudden I would hear her banging her head on the wall and screaming. When I found myself worrying about Denise causing serious harm to herself and others, I asked our social worker with Community Living Services to make an urgent referral for behavioural support. It still took months to access a behavioural consultant.

It's hard to find words to describe how difficult life was through those months. I felt hopeless and helpless as Denise continued to scream and cry day after day, bite her hand to the point of bleeding and hit her head on walls with framed pictures—hard enough to shatter the glass. My husband worried about our ability to continue to live with Denise and we both worried about the impact of our situation on our younger daughter. As though on a ship during a most horrendous storm, at times we could only hold on to each other tight and hope to get through it intact.

“Save the tough conversations for a quiet time.”

What helped the most?

There were afternoons where I spent all my time trying to prevent Denise from harming herself and struggled to even prepare a meal for our family. One day another parent came to my door with freezer meals. I cried with gratitude.

I was worried Denise might have something physically wrong that could be causing pain she couldn't tell me about. It was reassuring to have a pediatrician, who examined Denise from head to toe more than once, rule out the possibility that there was anything we were missing.

It helped to have friends who understood if I couldn't return phone calls or if I didn't feel like company because I was just too exhausted.

An experienced behaviour consultant came into our lives and spent time in each of Denise's environments. She was able to make recommendations that ensured consistency in how everyone interacted with Denise. We began to document how often Denise would scream and harm herself to see if there were clues as to cause.

We were very fortunate to have a school team that supported Denise and us as a family. Even though there were days that Denise was extremely distressed and disruptive at school, the staff knew that Denise's time at school was the only break I had.

I was very concerned about pharmaceutical intervention. I hated the idea of giving Denise drugs if there was any other way. I was relieved to find a psychiatrist who listened, who was cautious about prescribing medications and who was accessible to us when Denise had a negative reaction to a medication.

Denise had a large crew of people in her life as we struggled along. I learned how important it was to have someone at the helm. If our crew—however well intentioned—were all paddling as hard as we could but in different directions, we got nowhere. When we all started to paddle in the same direction, we made progress.

We are also very blessed to have a person, Leah, who has shared life with our daughter and family over many years in a variety of roles. Leah was a student in high school when she first entered our lives as Denise's babysitter. Years later, Leah was our after-school caregiver for several days a week. For a few years she was funded as Denise's life skills worker. Leah continued to support Denise and our family through the good times and the most difficult times, when no one had answers and it seemed like there was no end in sight. Leah continues to be a part of Denise's life.



I learned something extremely valuable about myself through that part of our family's journey. I struggled with feelings of failure—that if Denise's behaviour didn't improve, I must not be doing enough or that I must not have been doing the right thing. Those negative feelings wore me down and depleted me of energy. I learned to let go of those feelings a little at a time, and accept that I was doing the BEST that I could. And I began to learn that one of the most important things I could do was actually nothing—that what I needed to do was stop, and just breathe. I tried to take at least 15 minutes a day to sit somewhere quiet and breathe deeply. During that time I began to trust that things would work out the way they needed to. Our family has faced other challenges since, and when I find my head starting to spin with thoughts of things I should be doing and feelings of failure, I remind myself to stop, and just breathe. I'm grateful for that learning.

Where are we now?

Denise still lives at home with us. She has a suite in the lower part of our home and Leah, now in the role of community support worker, is with her throughout the week. With Leah's assistance, we have worked hard to ensure that there is consistency in Denise's life and have found a combination of medications that support her well. We have been able to develop a visual communication system so Denise can see what is planned for each day and week, and can make choices about what she would like to do. Denise leads a busy life in the community. She can be found many Mondays having lunch at a favourite restaurant, or on a Friday you might find her sitting in the front of a kayak being paddled around Deep Cove.

We know we might face difficult times again in the future, but we also know from experience that we'll get through them.

“Be heard, even if the message is hard for you to say and for others to hear.”

Denise's Story | Insights for Parents

Family

What your family may see:

- Challenging behaviour
- Lack of triggers for the behaviour
- Head banging
- Screaming
- Hand biting to the point of bleeding
- Feelings of hopelessness and helplessness from family

What a supported family can look like:

- Tirelessly supports the child and each other
- Supports other children in the family
- Advocates for help for their child
- Documents and records behaviour
- Provides consistency in their child's life
- Communicates clearly to professionals (with the help of a friend)

How you can help family members understand:

- Continue to talk to family members about the changes in your child
- Do not be afraid of expressing your needs to various family members

Family Friends

What friends may see:

- Family becomes isolated from friends
- Friends may see the behaviour as "manipulation"
- Friends have difficulty understanding the behaviour and may lose touch

What support looks like with friends:

- Organizes and provides meals for family
- Goes to meetings with parents to provide support
- Continues to call and offer support, even if the calls are not returned
- Reassures parents that it will not always be like this

How you can help friends understand:

- Ask for help with other children
- Ask family members to help with household tasks you are unable to perform
- Ask trusted family members to stay with your child so you can get out for a short time

School

What the school may see:

- Difficulty re-directing the student
- Behaviour at school becomes out of control
- Self-injurious behaviour is noted by teachers
- Children are often asked to not come to school

What support should look like at school:

- Provides extra support to allow child to remain in school
- Works with other professionals as part of the behaviour support plan (See p.9)
- Reviews and changes the individual education plan to meet the new needs of the child (See p.9)
- Reduces expectations of the student at this time
- Works with parents to provide consistency

How you can help the school understand:

- Always bring someone along with you to meetings
- Inform teachers of steps being taken
- Request safety plan/positive behaviour support plan (See p.9)
- Meet with counselors/teachers to reduce your child's school expectations

Professionals

What professionals may see:

- Changes in behaviour indicating changes in the child's well-being

What support should look like with professionals:

- Examines child to rule out physical problems
- Listens to parents and trusts they know their children best
- Prescribes and monitors medication; respects parents' requests
- Does functional assessment and provides positive behaviour support plan (see p.9)

How you can help professionals understand:

- Always bring someone along with you to meetings
- Log changes in behaviour, the times of day they occur, triggers and setting events (see p.9)

Community

What the community may see:

- Crying and tantrums in public when the child's immediate needs are not met

What support should look like in the community:

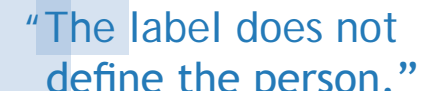
- Help is offered by a stranger at the grocery store
- Support organizations such as the Family Support Institute and The FORCE provide access to helpful books, videos and support groups (See p.19 for more resources)
- Mental health team in community living for children will offer therapy to children with dual diagnosis
- Ministry of Children and Family Development provides clinicians to work with your child

How you can help the community understand:

- Make moments in public an opportunity to educate others
- Build a community of support around you. This may include anyone who is interested in supporting your family at this difficult time
- Don't stop at your first attempt to find support

Denise's Story | Dictionary of Terms as Related to the Story

Behaviour Consultant	A behaviour consultant assesses the environment in which the child lives and builds a plan to help all caring adults allow the child to be successful.
Counselor	A clinician who provides support and counseling to your child. A counselor cannot prescribe medication.
Dual Diagnosis	Two diagnoses. In Denise's case it refers to an intellectual disability or autism with a mental disorder.
Developmental Delay/ Intellectual Disability/ Mental Handicap	All refer to the same disability, which is defined by an IQ under 70, as well as a low adaptive score (an ability to complete daily living tasks).
Individual Education Plan (IEP)	A plan written with you and the school team to provide your child with an education that is appropriate to his or her needs.
Positive Behaviour Support Plan	A plan designed to help everyone recognize your child's setting events, triggers, and how to manage your child's behaviour in a positive way.
Psychiatrist	A physician who specializes in working with people who have a mental illness. Because they are physicians, they are able to prescribe medications.
Safety Plan	A plan written at school, with your input, that will keep everyone including your child safe at school.
Setting Events	Setting events are those which may not be directly related to a behaviour, but can start a chain of reactions that leads to the behaviour. E.g., forgetting to take medication. They could also be called triggers.



“The label does not define the person.”



TEN ways People Could Help Your Family

They could...

- 1 Understand that everyone works through a difficult situation in a unique way
- 2 Just listen...without judgment
- 3 Offer to take your child out
- 4 Get together and plan some meals for you
- 5 Check in from time to time just to say hello
- 6 Offer to take your other children
- 7 Pick up things at the grocery store for you
- 8 Accompany you to the grocery store or on other outings
- 9 Make phone calls on your behalf
- 10 Accompany you to appointments

Nicole's Story | Dual Diagnosis from a Youth's Point of View

My name is Nicole. I am 22 years old and live in Surrey, BC, Canada. Because of my mild intellectual disability, I live in family care, which means I live with a family, and they care for me. In my own family I have three sisters and one brother. I live with a label of a dual diagnosis, which means that besides my intellectual disability, I also have a mental illness.

My life has not been easy. I was seven when my mom died in a car accident. We were returning home from a holiday when our car went out of control. Only my dad and I were wearing our seat belts. My mom, who was taking care of the baby Naomi, was thrown from the car along with my older sister, Blanca. My mom was taken to the hospital and died that night but the rest of the family was fine.

After that, my life changed forever. I was not given the chance to properly grieve for my mom when my dad remarried. With my dad's marriage came the responsibility of caring for my baby sister. I feel that much of childhood was taken from me from that time on. When I was ten I began to notice that I was not enjoying my life. I was crying easily, and would feel very angry inside. I argued with everyone, and would take my anger out on Naomi, the love of my life, by beating her up. I did not want to be with people and had no friends at school because I just could not be social. I felt that people just did not understand me, and I definitely had no desire to understand them. My dad took me to our local mental health team where I was seen by the psychiatrist who diagnosed me with depression. I was then put on the drug Luvox, and received counseling from a wonderful counselor.

When I was twelve, I was sent to my family's home country in Central America to live with my grandmother. In spite of my challenges, these were good years. At fourteen I came back to a large high school in Surrey. Once again, the bad feelings returned and I started to feel grumpy and sad inside. My neck started shaking uncontrollably, and I began to have physical pain. Once in a while, I would hear little voices calling my name or telling me to kill myself. I became very worried and started talking to a trusted teacher, who made a phone call to the adolescent crisis response team in our community. I met with an outreach counselor who became a very special part of my life during my illness. Meanwhile, my family doctor put me on the medication Paxil, and continued to adjust the dosage.

This continued until I was sixteen, when everything blew out of control. It started with a funny smell, and then I began having seizures at school and was rushed to our local hospital on a regular basis. Many people believed that I was just looking for attention, but I also had people who believed in me and accompanied me to the hospital. I was put on medication for my seizures, but I became very sick. I slept all day, would get up and eat, which would then make me vomit, and I would then go back to sleep. My strength left me and I would lose my breath doing my favourite activity, shopping. From there, my depression deepened and I started fighting at home, losing weight and not sleeping. I felt

“Do not judge me.
I am doing the
best I can.”

hopeless, like I was dying inside. I felt that I was on the outside of my body, watching myself waste away to nothing. I felt overwhelmed, as if I had a huge burden on my shoulders that was preventing me from moving. Once again, medications were adjusted but it made no difference to the quality of my life.

I started hearing little voices in the television calling my name. The voices were also in the radio telling me to kill myself. One night little gnomes were trying to attack me in my bedroom. I had a bicycle chain by my bed that I used to hit myself in the head. My dad was trying to keep me from hurting myself or anyone else in the house, but his efforts to stop my psychosis did not seem to work. Finally it just stopped—it was over—and I fell asleep. The next day, my dad removed everything from my room except the furniture and we began our journey to get help.

Since that time I have been hospitalized five times. I have seen four psychiatrists and am currently involved with a mental health team that specializes in working with people with a dual diagnosis. The professionals provide me with therapy, medication, and support. I have learned that not all professionals are the same. I appreciate the professional who listens to me, tries to get to my level of understanding by using simple words that I understand, and talks to *me* rather than my caregiver.

My recovery has not been fast. It takes time and patience to recover from a psychiatric crisis. Sometimes it felt like my life would never be good again, but I took those baby steps to get where I am. I was not always patient while waiting for my medications to work, but eventually my head became clear. Each day has given me opportunities to learn and grow. My greatest help in this journey has been having people to talk to when times have been tough. At school, that meant a “safe” person I could be with outside of the special education classroom. In my case it was my PE teacher who always allowed me to be a part of whichever PE class was going on in the gym at the time. In my classroom, it was a special teaching assistant who could talk me through a psychotic episode as if it was just a normal part of her day. My friends always believe in me and continue to include me in activities, even though I sometimes act a little weird. I only associate with people who value me.


I, on the other hand, now know my limits and try my best. I am still often accused of looking for attention, but people who love me know that I am doing the best that I can. Sometimes it takes a great deal of effort for me to be with people, but I know that this is something I need to do in order to maintain my mental wellness. I continue to educate myself on my illness and the medications I take, and am not afraid to ask questions or talk about my illness. I have accepted that it is OK to



be ill. I am realistic about my illness, and know that I will have it for the rest of my life. Your initial diagnosis may not remain the same, and your illness can change over your lifetime. This has happened to me, but I have learned that I can now control it, rather than have it control my life. My medication is crucial to my well-being, so I take it when I should and try to never miss a dose. I can get confused, so the pharmacist puts it in blister (bubble) packs to make it easier for me.

Today, I got up at six o'clock in the morning to go to a day program where I work and socialize with friends. Even though every day is a challenge, I take each day one at a time and live it to the fullest. In my free time I advocate for others with a dual diagnosis. I have spoken at teacher's conventions about the importance of believing in children. My religion plays an important role in my life, and I am an active member of our congregation. I live a life full of meaning. I have activities that I love to do and I feel that I have done very well. I am where I want to be in my life at this time. Not long ago I asked a friend of mine, "What if it doesn't get any better than this?" Her response was that if this is as good as it gets, I can still lead a full life working for my congregation and helping others. She was right!! But it did get better. In the future, I want to do more work in mental health and, most importantly, I want to help others. I am living life at its fullest.

Remember, only you can make your future—no one else can. Try your best and live life the best you can. Don't give up on yourself, because you are the best advocate for yourself. Even when others give up on you, believe in yourself because there is always hope.



"Forgive yourself
and others."

Nicole's Story | Insights for Youth

Family

How you might act with your family:

- You argue with your family
- You don't want to go to school
- You don't want to eat or sleep
- You cry a lot and feel sad
- You spend a lot of time in your room

What support could look like in your family:

- They believe in you and know that your behaviour is caused by your disorder
- They help others understand what you are going through
- They speak for you if necessary, and go with you to appointments
- They never give up on you

How you can help family understand:

- Keep a chart of your moods, what your body is doing, how you feel
- Encourage your family to help you chart your mood by providing grids with happy/sad faces

Friends

How you might act with your friends:

- You don't want to see your friends
- You lose interest in doing things you used to enjoy

How your friends could support you:

- Continue to come over and make you go out with them even if you don't feel like it
- Continue to phone and let you know what is going on in the world outside your home
- Visit you in the hospital
- Go out of their way to include you in activities both in and out of school

How you can help friends understand:

- Try to explain to friends what you are going through
- You may have to use pictures, symbols or feelings charts to let them know
- Keep in contact with your friends

School

How you might act at school:

- You lose interest in learning
- You cannot concentrate
- You forget what you have learned
- You do not want to go to classes
- You act out and become dangerous to yourself and others
- You become disruptive in class (laughing out loud, moving around)

What your school could do to support you:

- Provide a safe place or teacher
- Provide the teacher assistance support to allow you to continue to go to school
- Provide a safety plan to make sure everyone, including you, feels safe at school (see p.16)
- Provide a positive behaviour support plan (see p.16)
- Educate everyone on your illness

How you can help others understand:

- Keep a journal of how you are feeling
- Ask for reassurance from a safe person
- Continue to go to school even if you don't feel like it
- Be a part of the planning of your individual education plan (see p.16)

Professionals

How you might act with professionals:

- You complain of feeling achy and sore all over
- You talk about hearing little voices telling you to do things
- You complain of funny smells

What support looks like with professionals:

- Makes eye contact with you
- Listens to you when you communicate through speaking or with visual cues
- Speaks to you, not only your caregiver
- Uses language that you can understand

How you can help professionals understand:

- Take your mood chart when you go to the doctor
- Communicate your feelings and moods
- Be an active part of your doctor appointments; ask questions

Community

How you might act in the community:

- You seem disoriented and unable to find your way around
- You lose interest in favourite activities
- You lose interest in going into the community. Want to stay home all the time

What support looks like in the community:

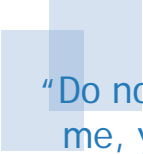
- A safe person who you can talk to; this could be your parent, a teacher, a counselor, your friend's parent
- Visits you in the hospital on a regular basis

How you can help the community understand:

- Try to be with someone who believes you and believes in you; this could be a friend, peer counselor, brother, sister, or a trusted adult
- Continue to force yourself to participate in activities even though it is very difficult

Nicole's Story | Dictionary of Terms as Related to the Story

Adolescent Psychiatric Unit	A unit in the hospital for youth twelve to nineteen years old who are struggling with a mental disorder.
Counselor	A counselor talks with you and works with you to help to make you feel better and be better able to cope with your life.
Diagnosis	After talking to you and watching you, doctors will tell you and your parents what is wrong and the best way to help you.
Dual Diagnosis	Dual means two. A dual diagnosis refers to an intellectual disability with a mental disorder.
Individual Education Plan	It is done at the school to enable you to do your school work.
Positive Behaviour Support Plan	It assists people to understand what makes you tick, and allows you to be supported in a respectful manner.
Psychiatrist	A doctor who specializes in working with people who are having scary or troubling thoughts and feelings.
Psychosis	Seeing and hearing things that are not really there.
Safety Plan	A personalized plan written by school personnel in context with parents or caregivers. It helps the school to recognize what makes you angry or anxious and helps keep everyone, including you, safe.



“Do not try to change me, you have no right. Help me learn what I want to know.”



TEN ways People Could Help You

- 1 Parents can advocate for you and help you advocate for yourself
- 2 Parents can get you the professional help you need
- 3 Education assistants can help you with your work at school
- 4 Teachers can help you to express yourself and provide you with alternate ways of communicating
- 5 Teachers can make adaptations to school work/homework
- 6 Teachers can provide you with a “safe” place or person at school
- 7 Professionals can provide a safety plan and a positive behaviour support plan for home, school and the community
- 8 Friends can call you and continue to visit
- 9 Friends can help you at school and help you get around the school
- 10 Friends can take you out to your favourite places

Other Ways People Could Help You

Family

- Advocate for you at school and with other professionals
- Be involved, with you, in writing your individual education plan and your positive behaviour support plan at the school

Friends

- Help you understand what is going on in the classrooms
- Help you get from one place to another in the school
- Support you in spite of your behaviour
- Try to learn more about your illness

School

- Reduce the expectations at school
- Realize that sometimes it takes all of your energy just to be there
- Give you a safe place to be when you need a break
- Provide extra Educational Assistant support

Professionals

- Family doctor will ask and answer questions and may prescribe medication
- Counselor will be someone to talk to
- Emergency room staff may be your first contact in the hospital
- The Adolescent Psychiatric Unit is a unit in the hospital where you may have to stay while the professionals observe your behaviour and adjust your medication

Friends of the Family

- Take you on community outings to favourite places
- Continue to phone and let you know what is happening in the world outside your home
- Accompany you to appointments
- Go out of their way to include you
- Support your family while you are ill

Resources

Websites

- **BC Association for Community Living**
www.bcacl.org
- **Dual Diagnosis Help**
www.dimagine.com
- **Family Support Institute**
www.familysupportbc.com
- **FORCE Society for Kids' Mental Health**
www.bckidsmentalhealth.org
- **JP Das Developmental Disabilities Center**
www.ualberta.ca/~jpdasddc/INDEX.html
- **The National Association for the Dually Diagnosed**
www.thenadd.org
- **Developmental Disabilities Association of BC**
www.develop.bc.ca

Additional Tools That May Be Helpful

- **West Coast Mental Health** - Works with dually diagnosed youth over the age of fourteen
Phone 604-660-0786
- **The BC Children's Hospital Family Resource Library** - Resource library which lends to parents
Phone 604-875-2345 Local 7644 | Email bookstore@cw.bc.ca
- **Transition Planning for Youth with Special Needs: A Community Support Guide**
Available online at www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf
- **Your Future Now: A Transition Planning & Resource Guide for Youth with Special Needs & Their Families**
Available online at www.mcf.gov.bc.ca/spec_needs/pdf/your_future_now.pdf
- **FRIENDS for Life** - Anxiety prevention and treatment workbook for children aged 7 to 11 years
Government Publication Services; Queen's Printer, British Columbia
To order: Phone 1-800-663-6105 | Email QPPublications@gems5.gov.bc.ca
- **Taming Worry Dragons** - A manual for children, parents, and other coaches
Garland, E. Jane; Clark, Sandra L.; Earle, Vicki (Illustrator), 2000
To order: Phone 604-875-2345 Local 7644 | Fax 604-875-3455 | Email bookstore@cw.bc.ca
- **Worry Taming for Teens**
Garland, Jane E.; Clark, Sandra L.; Earle, Vicki (Illustrator), 2002
To order: Phone 604-875-2345 Local 7644 | Fax 604-875-3455 | Email bookstore@cw.bc.ca

