


Focus on Families

Autumn 2005

Welcome to Focus on Families
Empowering and encouraging families
to take an interactive role in their
son/daughter's health care.

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Autumn greetings to all families! We are so pleased to offer you this edition of *Focus on Families* to address health care issues specifically. We're going to talk about: relationships with health care professionals, access to health care, and explore new ways of thinking about health as a concept.

Doctors in Manitoba have recently received a Fact Sheet from Community Living - Manitoba. A copy is included in this newsletter for you. It includes basic information about the Vulnerable Persons Living with a Mental Disability Act and introduces Community Living —Manitoba, as a resource. The information is meant to both inform and open a dialog between our organization and health care professionals. Our hope is families will take the opportunity to do the same.

Ideally the doctor/patient relationship is a dialog in which each person talks *to*, not *at* the other, and then listens carefully to what he/she has to say. Experience tells us that this can be a challenge. Doctors, individuals and their families and advocates make up the health care team. Each person's health care team is a necessary part of his or her life.

Our hope is that as families you will be able to use this information as a tool to strengthen understanding, gain confidence and help your son or daughter move towards a more mutually respectful relationship with their health care professionals .

The best six doctors anywhere
and no one can deny it
are sunshine, water, rest, and air
exercise and diet.

These six will gladly you attend
if only you are willing;
your mind they'll ease
your will they'll mend
and charge you not a shilling.

— *English Nursery Rhyme*

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Attention: Medical Professionals

*Mailed to every doctor in the province
(together with an covering letter)*

It is likely that people with an intellectual (or mental) disability are part of your practice. The following will provide you with important information.

➔ *The Vulnerable Persons Living with a Mental Disability Act (VPA)* was proclaimed by legislation in 1996 protecting the right of people with intellectual disabilities to make their own decisions, live in the community, and gain access to services that non-disabled people do.

➔ The term 'intellectual (or mental) disability' refers to people with a lowered IQ who may require some kind of support to adapt to every day community life. Note that the historical label, mental retardation, is no longer part of accepted vernacular nor is it the term used under the law. According to the legislation and supported by Canadian statistics, it is fact that the larger portion of people with intellectual disabilities can make their own decisions with support from people that they trust.

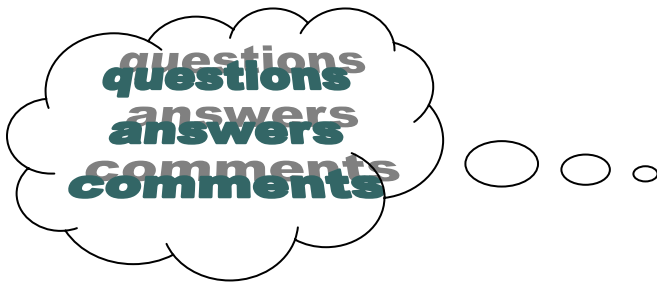
➔ As a last resort, the VPA does allow for a *Substitute Decision Maker (SDM)* to be identified when the vulnerable person has a decision to make and is unable to do so even with support. 'Substitute Decision Maker' is a legal status and can only be confirmed by the Office of the Vulnerable Person's Commissioner. If your patient falls under the VPA please determine if he or she has an SDM and include this person in the patient's health care decisions. Even when there is an SDM, the individual is to be consulted and included as part of the decision making process.

➔ The proclamation of this legislation has highlighted the need to protect this vulnerable population from abuse and neglect

This population is at high risk of being abused. The abuser is often a person he or she knows and is in a position of power and trust. If you know of or suspect abuse or neglect, we encourage you to take action by contacting your local Manitoba Family Services & Housing office.

For more information, resources or the identification of possible support people in your area contact Community Living-Manitoba at 204-786-1607 or visit the website at www.aclmb.ca

Community Living-Manitoba *is dedicated to the full inclusion in the community of persons of all ages who live with an intellectual disability.*



1. Why is it important to talk to my doctor?

Whether we like it or not, along with the job of raising a child with an intellectual disability comes the responsibility of advocating on his/her behalf. One of the things that makes our job more challenging is negative attitudes. These become a barrier to our child's full participation. We learn that teaching and sharing information with others helps to counteract the negative and outdated attitudes we face. We have the opportunity to impact, in a positive way, on the way health professionals think about our kids. Without knowing it, our efforts will also support those individuals who don't have strong advocates or family. By bringing our information to doctors, our collective voice can help raise the profile of health care issues for people with intellectual disabilities in general

2. My doctor is so busy. He just doesn't have time and I don't want to become a bother.

Our doctors need to have all the information in order to make good health care recommendations to us. Make a separate appointment if you need to just to talk and ensure that he/she has all the information. Take this newsletter and refer to the Fact Sheet that Community Living - Manitoba sent out. It's meant to get the discussion going. And then be vigilant in ensuring that such discussion is ongoing. If for some reason your doctor does not meet with you or understand the importance of the information that you have to share, then perhaps you need to discuss with your son/daughter the possibility of finding another doctor. Our hunch is however that when we are clear and speak about our needs to our health professionals, they respond appropriately.

3. The group home staff tell me that my son doesn't want me included in his medical appointments . . . How can I find out what's going on? He may not need an SDM but he's still my son!

He IS still your son and that will never change. However, our kids grow up and sometimes have things going on in their lives that they choose not to share with us. Remember, the primary relationship here is between your son and his doctor. Make sure that he has help, support, and advocacy if he needs it. And then step back. One of the most challenging things for us as parents to learn is to back up a step or two and allow our adult children to live their own lives. Our role as supporters and advocates needs to be lifelong. But we are also challenged to learn to walk that fine line between being involved, hovering and supporting in a different way. It's a growing experience for our adult children, and us too!

4. The truth is I'm really intimidated by my ten-year-old daughter's doctor. She is hard to talk to.

A totally understandable feeling. Have you told her how you feel? As parents we have been conditioned NOT to challenge professionals. We have been 'trained' to see professionals as experts and assume that they know more about our sons/daughters than we do. We have given our power over to psychologists, social workers, teachers,

and counsellors for years. We are beginning to understand though that we have an important and critical place as part of the health care team, if not by birthright most certainly through history and life experiences. Make it clear that you want and need to be part of your daughter's health care team. If your doctor does not respond or you

are not able to move beyond these feelings, then perhaps you need to find another doctor. Don't give up too quickly. Consider bringing another person with you to the appointment for support. Choose someone who your daughter and you both trust. Addressing this situation may help both you and your doctor.

Do persons with intellectual disabilities in Canada have equal access to health and health care?

As we begin thinking about this issue, it's helpful to understand some facts that have been identified through various research studies in the United States and the United Kingdom. Read through the following points and put a check next to the issues that you think may affect your family member.

Did you know that . . . ?

- 15% of people with intellectual disabilities take two or more psychotropic drugs at the same time. This increases the risk of drug interactions, leading to sedation, increased confusion, constipation, reduced ability to walk or stand upright, falls, etc.
- a health care professional may think that a real health problem is "just part of the disability" and may not treat it seriously.
- people with intellectual disabilities often have a difficult time telling their doctor what is wrong with them. Some don't realize what "pain" is and may not realize that it is not a normal state. Some can't tell anyone where the hurt actually is. It is especially challenging for people who are unable to communicate with any words at all. All of this may make an accurate diagnosis difficult or impossible.
- communication difficulties may mean that it will take a health care professional much longer to deal thoroughly with the person. Standard medical practices may not be equipped to accommodate.

Being vulnerable doesn't have to be threatening. Just have the courage to be sincere, open and honest. It creates self-empowerment and the kind of connections with others we all want in life.

— Sarah Paddison

- as a group, persons with intellectual disabilities have a greater variety of health care needs compared to persons of the same age and sex in the general population. These may include: high blood pressure, obesity, congenital heart disease, abdominal pain, respiratory disease, cancer, gastrointestinal disorders, diabetes, chronic urinary tract infections, thyroid disease, dental and mouth problems, etc.
- many health care professionals do not know enough about the ways in which services and supports can help either cause or solve health related problems.

Studies referred to above have demonstrated that parents and advocates must take on an advocacy role if the person is to get adequate health care.

. . . and that is where we come in.

This information is not intended to frighten families. It is meant to identify the issues so that we can take control over the problem and build strategies for solutions.

We **can** help protect our sons and daughters by informing ourselves and becoming part of the medical team. We have important information for doctors and other health care professionals.

It's time for us to find our voice and use it!

(parts of this excerpted from "Draft Position Paper on Equal Access To Health and Health Care for Individuals with Intellectual Disabilities And their Families" written by David Jory, CACL Health Care Working Group Chair 2003-04)

Broadening

the Definition of Health



As a society we are beginning to go beyond what we have perceived as conventional health care. We have begun to explore what's "out there" and are beginning to expand our definition or concept of what constitutes "good health." We've come to understand that health in general involves more than just our physical bodies.

We are continually challenged to look at ourselves from this broadened perspective —

Our mind: our intelligence, our capacity to adapt, the ability to problem solve

Our body: the level of discipline we have, the value of putting good foods into it, it is what it is — leaky and lumpy sometimes

Our heart: the emotional/passionate side, the part that connects us to humanity, the loving caring side

Our spirit: our connection to the universal energy, our conscience, our inner voice, that "gut feeling" we get (and too often ignore unfortunately)

When we acknowledge all the parts of ourselves it is possible for us to shift our beliefs, which then enables us to move from reacting to our dis-ease to actually preventing it. We are learning that when we examine all parts of who we are we open ourselves to

being more willing to integrate different types of models in the healing arts. The continuum of healing options is extensive when we go exploring.

We are all wondrously made, each of us unique. Each of us given a long list of things to believe in as we grow up, from our families, our classmates, teachers, co-workers, our culture, our history, etc. Moving into new ways of looking at our health often requires shaking up our paradigm tree. That requires going against popular thinking, deeply imbedded societal belief systems, and doing that does take courage.

Society is beginning to recognize that there is more to health than conventional medicine. We want to make sure that our sons and daughters have access to the range of options and are included in this expanded way of thinking.

In order to ensure this, we as families and advocates need to be well informed and up to date. Exploring ways to integrate different models of health is a beginning. Integrative medicine involves all the other forms of the healing arts that are from time to time referred to as complementary or alternative medicine.

Moving from conventional thinking and practices to a more integrative approach to health requires shifting — from treating only our symptoms in some specialized

manner to recognizing that we are dynamic beings with a complex energy field affected by many factors and patterns. It also requires taking responsibility for our health and working *with* health professionals instead of only letting them work *on* us.

Good health is gaining and maintaining some balance. It's about bringing together every aspect of ourselves and ensuring that each is cared for and adequately

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nourished. This is at the core of our health and for our family members with a disability!

We've included some things to consider. Please do so with the knowledge that information and data alone will not heal us, taking medication alone will not cure our disease, diet, exercise, healthy food choices, meditation or prayer, all of these alone will not heal us. It is the experience of that information that will help heal us at some level, along with a belief that we deserve to be healthy and happy.

Please feel free to use the information in a manner that is most helpful to you and your family.

An Assortment of Therapies

If we indeed do bring our experiences into any information we gather and it heals us, in what way do new facts and data impact us? Taking charge of our health (and our life) means exploring **new ways of thinking**. Each time we open ourselves up to information we not only attach experiences to them, along side come any beliefs that either affirm or deny data the comes our way.

For example if we have always dealt only with main stream medical professionals we tend to think that anybody outside that realm is a "quack" and don't give much credence to facts that contradict such thinking. On the other end of the medicine spectrum, if you were raised to believe that certain **natural herbs** help alleviate some physical symptoms you might be suspicious about taking a prescription which you don't know the in-

redients of. Neither are wrong or right. They are simply a response based on our experiences.

First, we need to decide what is it about medicine and health that we do believe. Is it *our* belief, or simply one that we have accepted because others told us so? **Taking the step** and exploring different ways of thinking can only give you new ways of obtaining good health. What follows is terminology that offers such an expanded view.

Most of us have heard the terms **complementary** and **alternative** medicine. What do they mean and are they different from each other? In fact, they are different, yet both may be used in a preventative capacity. Complementary medicine is used *together with* conventional medicine and might include using **sacral cranial therapy** to help a patient overcome the affects of anaesthetics following surgery. Alternative medicine is used *in place of* conventional medicine. An example might be using a **special diet** or **natural treatments** to treat gallstones instead of undergoing surgery.

There is a another term being used called **integrative medicine** which combines mainstream medical therapies and complementary and alternative medicine therapies for which there is some high-quality scientific evidence of safety and effectiveness. Obtaining good health shouldn't require an either/or situation but part of the full package of how we achieve a well-balanced and healthy lifestyle. At some point we all require the help of a main stream medical professional to provide a diagnosis, which may lead us to a specialist. That same specialist may also have training and expertise that leads us to better nutrition or meditation. Europe and Asia, for example have long used **herbs**, **massage**, and **prayer** in their hospital settings as a means of integrating different methods of healing. Again, if we believe or know something will help us, chances are good it will. Here are three categories of integrative medicines. At a minimum we encourage you to consider all ways of obtaining good health. By now most of us know that our life's not worth anything without it.

1. Alternative Medical Systems

Alternative medical systems are built upon complete systems of theory and practice, often developed separately and earlier than the North American conventional medical approach. Examples of alternative medical systems that have emerged in Western cultures include **homeopathic** and **naturopathic** medicine. Examples that were developed in non-Western cultures include traditional Chinese medicine and Ayurveda (India).

2. Mind-Body Interventions

Mind-body medicine uses a variety of techniques designed to enhance the mind's capacity to affect bodily function and symptoms. Some techniques in this area have become mainstream (for example, patient support groups and cognitive-behavioural therapy). Other mind-body techniques considered include meditation, prayer, mental healing, and therapies that use creative outlets such as **art**, **music**, or **dance**.

3. Biologically Based Therapies

Biologically based therapies use substances found in nature, such as **herbs**, **foods**, and **vitamins**. Some examples include dietary supplements, herbal products, or specialized diets. The Canada Food Guide has over the years been upgraded to reflect findings of research and cultural diversity.



One Family's Story

An example of integrating new ways of thinking

Janie is a 25-year-old woman who has Down syndrome. She lives at home with her family and is involved in several part-time volunteer and work positions during the day. Janie has suffered with acid reflux for the past 8 years. Janie's parents have taken Janie to several doctors and specialists over the years and she has also tried various medications. It's even been suggested that Janie undergo some minor surgery to attempt to solve this very challenging medical ailment.

Last year a neighbour suggested to Janie's mother that she explore some alternative measures in hopes of solving Janie's physical problems. The neighbour knew another woman with similar issues that had experienced profound relief by receiving

therapy sessions from a massage therapist who was trained in several therapeutic modalities. Janie's family had always dealt with their health care issues in a traditional way so this was a new way of thinking for them.

When Janie had her first appointment with a licensed massage therapist

she was uncomfortable having her body touched. It didn't take long before she began to trust her therapist even looked forward to her weekly appointments. Within that first month, the family noticed changes in Janie's overall health, energy level and acid reflux problems. She had to wake up less at night and was able to digest her food more easily than ever before.

That first year, Janie and her mother explored several other alternative healing options. They took Qi-Gong ("chee-gung") classes and learned to meditate. Janie had a difficult time doing that initially until the instructor helped her adapt the quieting process by introducing music and visual

images. The whole family learned more about the "healer within" their own bodies and began making healthier choices in the foods they ate together.

As a family they also planned weekly family nights that included a variety of activities, sometimes swimming, walking on the park path, shooting baskets at the local school, going to the museum or movies—

always together. Within 18 months, Janie's acid reflux problem was gone.

Eight years of conventional medicine was not able to address this issue satisfactorily. In addition, Janie's whole family had become involved in a variety of integrative health care activities. Janie's father reduced his blood pressure, Janie's sister

lost weight, and her mother discovered a renewed energy that she had not felt since young adulthood.

This family's discovery about the benefits of alternative/complementary (integrative) medicine is a typical experience. Once they took responsibility and control of their own treatment and health, they began also to understand how to live their lives in a more balanced manner. By addressing all parts of who they are — body, emotion, spirit and intellect they could more easily prevent disease in their lives. In exploring alternatives with Janie the entire family benefited.

It didn't take long before she began to trust her therapist, even looked forward to her weekly appointments.

Don't forget to laugh — It's the best medicine.

I work so hard to stay in shape. Whenever I read anything, it says, "Consult your doctor before doing any exercise." It always says that. Does anybody do that? I kind of think my doctor has people coming in with serious problems. I don't think I should be calling him and saying, "Hi, this is Rita, I'm thinking of bending at the waist."

— Rita Rudner



What's it all about Alfie?

Okay, so . . . What does this all mean? This special edition of Focus on Family opens the door so that we can take a closer look at some things we knew, and a first look at some things that **are** new in relation to health care. Now let's take a moment to review . . .

We read about some **Canadian statistics** which suggest that persons with intellectual disabilities may not have equal access to health care. It is not there to frighten us but rather to reinforce the importance of our educating (and advocating) for ourselves. The more information we have, the more confident we are likely to be in speaking up and being part of the health care team. This is especially important for our family members with a disability, as they are become stronger self-advocates.

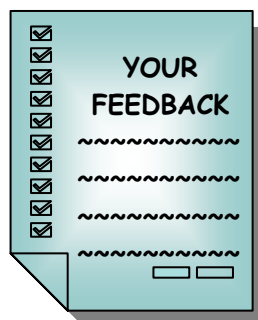
We read **some questions and answers** that remind us how important advocacy is. It's not only about the doctor being too busy. It is also about how we make the time to speak with the doctor. It's not about our feelings of intimidation but rather how

we are going to work through them to ensure we are in fact part of the health care team.

We presented and explored an **expanded definition of health and health care**. More than our bodies contribute to our wellness or our "dis-ease." Our understanding of how our minds, our hearts and our spirits are all a piece of our collective "health."

We introduced an **assortment of therapies** and other health related options — some new, some old, some different — thoughts and ways of dealing with our health.

We read **Janie's story** and got a picture of how connecting to some of those alternatives helped one woman relieve painful symptoms and got the whole family living a more healthy balanced lifestyle.



In the meantime we wish you all good health, balance, and happiness.

Think About Talk About

We're left with a few things to think about and talk about with our families, with our friends and most importantly **with** our health care professionals. For example:

- *What other things could be changed in my life (son or daughter's life) that might help create a more balanced approach to comprehensive health care?*
- *Who are some people right here in my community that I could talk with?*
- *What do I need in order to feel more comfortable speaking openly and confidently with my/our doctor?*

As always, Community Living - Manitoba would love to hear from you. Has this been helpful? What other kinds of things would be helpful? We encourage you to share any stories or experiences that you'd like to. It's amazing how supportive it is for families to hear from other families because when we hear how other people were able to overcome their challenges we are inspired to overcome our own. Whether it's about health or other topics we want to hear from you.