



## Chapter Seven

# The Medical System

When advocating for your child with a disability in the medical system, the first thing to remember is not to be intimidated by professionals. You know your child better than anyone else. At the same time, doctors are professionals in their fields so collaborating effectively with doctors is the most beneficial way to make sure that your child receives the best care possible. Make sure that all medical professionals provide you with the information you need and the time to ask questions. If you do not feel right about what one doctor has said, seek a second opinion.

### Choosing a Good Doctor

The most important thing you can do is to choose a good doctor. If you have a committed doctor who is willing to do the research and make sure that your child receives the best medical treatment, you will feel more at ease with the options and recommendations. Beyond this, you will need a doctor in order to fill out forms for your child, such as for the Disability Tax Credit (note: there may be a fee for this).

**Tip:** Since children with intellectual disabilities sometimes face complicated medical challenges, it may be helpful to have a pediatrician as your child's regular doctor. You can phone the health region to see if there are local pediatricians accepting patients. Be aware that this can be a difficult process, but keep checking in as patient caseloads can change. A general practitioner can be effective as a pediatrician, however, many GP's do not have the in-depth experience needed to deal with developmental issues.

### Keeping a Medical Journal

A journal of every step in your medical journey will help you to keep track of essential information produced out of visits with health professionals. A journal can also help you advocate for your child later down the road and help new doctors understand your perspective of your child's history. The doctor will be able to assess the information and make a more accurate diagnosis. It will also help doctors to understand the struggles you have gone through. Sometimes people with intellectual disabilities have their symptoms minimized or overlooked. A documented history may help your doctor recognize certain symptoms and that your child needs and deserves thorough, respectful medical treatment.

**Tip:** Do not assume that a doctor or nurse will know how to support or accommodate your child during an examination, especially if it is a first visit. Ask for extra time when you book the appointment. They may have textbook knowledge of your child's disability, but they do not yet know your child. If your child is sensitive to sounds, touch, new people or new environments, let the medical staff know and inquire about accommodations that can be made to ensure your child is as comfortable as possible.

## 7.1 Alvin Buckwold Child Development Program & Wascana Rehabilitation Centre

If you have a child with an intellectual disability, you will most likely be referred to early intervention services at one of these central rehabilitation centres in the province: The Alvin Buckwold Child Development Program (ABCDP) or The Wascana Rehabilitation Centre (WRC). The Buckwold program is located in Saskatoon and serves the northern half of Saskatchewan whereas the Wascana Centre is in Regina and serves the southern half of Saskatchewan.



### **Alvin Buckwold Child Development Program**

The Buckwold Program offers assessments, diagnoses, consultation, and treatment for children with intellectual disabilities. The staff includes medical specialists, clinical dietitians, nurses, pediatric occupational therapists, pediatric physiotherapists, psychologists, social workers, speech-language pathologists, and therapy attendants. Sometimes, Buckwold staff travel to northern and rural communities, so it is possible that you could be served at home. Contact Buckwold to find out.

### **Wascana Rehabilitation Centre**

The Wascana Centre facilitates diagnoses and offers clinics, consultation, therapy and information. The staff includes medical specialist, clinical dietitians, nurses, pediatric occupational therapists, pediatric physiotherapists, psychologists, social workers, speech-language pathologists, and a music therapist. There are also seating and equipment technicians to fit children with assisted-living devices. For parents of children with disabilities, they offer a family resource centre and parent support services.

Entering this system and receiving a diagnosis for your child can be intimidating and overwhelming so we suggest that you take someone with you. It may take a number of appointments before your child's assessment is complete. Once the assessment is done, you will work with the staff to develop goals and a plan for your child. The staff will also refer you to programs in your area. Before each visit, we recommend you:

- Write down your questions before you go to your child's appointment.
- Always let the staff know what your concerns are.
- If you do not understand the doctor's or therapist's explanation, ask them to explain it again.
- Give the doctor all the information you have. This will help the staff do a proper assessment.
- Fill out all the information on the forms you are given; it makes the process faster.
- Make sure that all information on forms, including addresses and phone numbers are up to date.
- If you are expecting to hear from the center and have not, call and ask what is happening.
- If there has been a miscommunication of any kind, do not hesitate to ask questions.
- If you are travelling for more than 40 km to get to an appointment, ask for a letter from center staff stating your appointment date. This will help you claim your travel expenses under the Medical Expense Tax Credit

## **7.2 Therapeutic Integrated Pediatric Services**

For those living in the northwest region, the Saskatchewan Health Authority provides a coordinated team approach for identifying developmental concerns in children from birth until they go to school. A Therapeutic Integrated Pediatric Services (TIPS) team may be composed of physiotherapists, occupational therapists, speech language pathologists, early childhood psychologists, KidsFirst, early childhood services, the school division, and public health nurses. First Nation Services provides TIPS services in Meadow Lake, Lloydminster, and North Battleford. More information about TIPS can be found on the Saskatchewan Health Authority's website.

## 7.3 Telehealth

Telehealth is a tool provided by the Saskatchewan Health Authority to improve access to health services. Parents can talk with their child's specialists using video conferencing links instead of traveling back for extra meetings. Doctors can use Telehealth for appointments, consultations, follow-ups, meetings, and educational sessions. If it will make your life easier to not have to travel, ask your doctor about Telehealth.

## 7.4 Employment Insurance Compassionate Care Benefits

One of the most difficult times for anyone is when a loved one is dying or at risk of death. By applying for Employment Insurance (EI), you can take up to a six-week leave of absence from work, to take care of a loved one that is ill. The EI benefit is called Compassionate Care Benefits. You are eligible if your relative is gravely ill and at risk of dying in the next six months and you have not claimed EI in the last year. A family member can share the leave of absence with you. This means that your mother, husband, wife, etcetera could each take off two weeks and you could take off two weeks to care for your child, but the total must be no more than six weeks. You can spread the six-week leave of absence over six months.

When you apply, you will need a medical certificate signed by a doctor as proof that your family member is gravely ill and needs your care and support (a nurse can sign the form if you are in a northern community where a doctor is not available). Then you must submit the form and proof of recent or current employment (pay stubs, or a record of employment) to your local EI office. You will also need your social insurance number, personal identification, and information about your family member and an explanation of the situation if you were laid off.

## 7.5 Jordan's Principle

Jordan's Principle is intended to prevent First Nations children from being denied essential services or experiencing delays in receiving them. Jordan's Principle applies to all First Nations children, status or non-status; involves all jurisdictional disputes, between federal departments or between federal and provincial governments; and provides payment for necessary services by the government or department that first receives the request. A parent or guardian of a First Nations child can make a request for services by contacting the Jordan's Principle toll free 24 hour line at 1-855-572-4453 to get more information and an application form.

## 7.6 Prescription Drugs

It can be a difficult decision to explore using drug therapy for your child. Prescription drugs can balance a person's system or ease some of the physical discomfort that comes along with certain disabilities. Drug therapy can sometimes be non-health related and end up as a way of helping to manage a child who has challenging behaviours. Using drug therapy to help manage behaviour is not necessarily wrong, but parents need to be cautious with any drug. It is important to ask questions about why the particular drug is being prescribed, and the side effects.

### Ask Questions

Always ask questions about any newly prescribed medication. Consider asking the following:



- **Why do you want to give my child this particular drug?** Ask the doctor if they have prescribed this drug to other patients and how it worked.
- **What are the benefits of the drug?** Ask the doctor about this drug's effectiveness and why it will benefit your child.
- **Could this drug interact badly with other medications or therapies my child takes?** Giving full disclosure about any medications, herbal remedies and therapies your child receives will help the doctor to assess any potential interactions. You can also double check drug interactions with a pharmacist. Pharmacists know the details about drugs that are on the market.
- **What are the possible side effects that my child could have while taking this drug?** Ask about short term and long term effects. You can also ask if a drug affects behavior, eating habits, sleep patterns, weight gain or thought processing.
- **Does this prescription's dosage match my child's weight?** Sometimes children with disabilities weigh less than other children the same age do, and they may be prescribed too high a dosage.
- **How much does the drug cost?** Under the Saskatchewan Children's Drug Plan, families pay a maximum of \$25 for prescription drugs if their children are 14 and under. But for older children and adults, not all costs are covered by the Saskatchewan Drug Plan. Sometimes there is a generic equivalent drug, at a much lower cost.

## 7.7 Prescription Drug Plans

### The Saskatchewan Drug Plan

Saskatchewan residents with valid Saskatchewan health coverage may be eligible for drug plan benefits. Costs of prescriptions vary depending on the type of benefits individuals receive. The pharmacist will submit prescription drug claim information to the Drug Plan claims system online at point of purchase to determine eligibility and whether or not it can be approved for payment or partial payment.

### Children's Drug Plan

The program allows families with children 14 years and under to pay \$25 per prescription for drugs listed on the Saskatchewan Formulary and those approved under Exception Drug Status. Ask your physician or pharmacist if any of your child's medications qualify for Exception Drug Status. If you already pay less than \$25 per prescription for your child, you will continue to do so.

## 7.8 Additional Programs to Assist with Coverage

### Supplementary Health Benefits

If people with intellectual disabilities qualify for Income Assistance or SAID benefits (they can apply when they turn 18), the Income Assistance Worker or Assured Income Specialist will nominate them for Supplementary Health Coverage and the Ministry of Health will send a letter once they have been approved. Once approved, their Health

Card will identify that they have Supplementary Benefits when they access health related services such as the pharmacy, doctor, dentist, eye doctor, etc. If there are any questions about benefits, call the Supplementary Health Program directly at 1-800-266-0695.

**Tip:** If a person is a member of a First Nations and holds a Treaty Card, all of their health needs will be covered by their band/reserve, and they will not receive Supplementary Health Coverage.

### Family Health Benefits

These benefits are for low-income working families who meet an income test

### Palliative Care Drug Coverage

This program helps cover the costs of prescription drugs for palliative care patients.

### Special Support Program

This is an income tested program helping low-income people with the high cost of drugs.

## 7.9 Medical Decision-Making For Self-Advocates

Inclusion Saskatchewan has created a series of plain language guides to help adults with disabilities with medical decision-making in clinical settings. One example is the Health Passport in which the essentials about an individual's medical background, care preferences, and ability to consent to health care treatment can be recorded ahead of time and provided to health care professionals when needed. These documents are available on the Inclusion Saskatchewan website at: [www.inclusionsk.com/resources](http://www.inclusionsk.com/resources)

## 7.10 Assisted Living Devices

In order to participate in daily activities, some people with disabilities use assisted living devices and aids. These devices help with communication, mobility and agility, hearing, seeing, eating, breathing, accessing buildings, and personal care. Many assisted living devices and aids are available and paid for through the Ministry of Health.

### Saskatchewan Aids to Independent Living

The Saskatchewan Aids to Independent Living (SAIL) program provides medical equipment, supplies and services that help people with long-term disabilities be more independent and active. SAIL covers a wide variety of assistive devices such as wheelchairs, walkers, specialized crutches, toileting equipment, transfer tub seats, commodes, bathtub lifts, hydraulic lifts and swings, orthopedic equipment, respiratory equipment, and feeding pumps. Eligibility is based on assessed long-term need. Most items are loaned, not sold, and must be returned to an authorized service provider for maintenance or when no longer needed. For more information, call toll free at 1-888-787-8996.

SAIL also provides special benefits for people with certain disabilities. The Paraplegia program covers additional drugs, incontinence supplies and specialized equipment for people with cerebral palsy, muscular dystrophy or spinal cord injury or disease. These patients are also eligible for home access and vehicle modification grants to facilitate community living. The Ostomy program covers ostomy supplies for those who have a urinary or bowel appliance and who have been referred by an enterostomal therapist. The Aids to the Blind program loans equip-



ment for people who are legally blind, such as magnification aids, low-vision glasses, brailers, and white canes. The program also provides some assistance with the purchase of talking or braille watches, talking scales, large button or talking phones, talking labelers, digital playback units and multifunctional electronic devices. The Canadian National Institute for the Blind (CNIB) registers clients who are eligible for the Aids to the Blind Program.

### **SaskAbilities & The Wascana Rehabilitation Centre**

If a doctor prescribes a certain type of device for your child, take the requisition to an authorized service provider to get the item. The two most common providers are SaskAbilities and the Wascana Rehabilitation Centre (WRC). Both SaskAbilities and WRC also provide orthopaedic services, including specialized seating for wheelchairs, custom-built footwear, splints and artificial limbs.

### **Respiratory Equipment**

Respiratory equipment is centralized at the Respiratory Benefits Depot at the Saskatoon City Hospital. You can order the equipment at the hospital or by mail to the Respiratory Benefits Depot with approval from the prescribing physician. Most items that are issued by the Depot will be maintained, repaired and replaced by them; this is all covered under the SAIL program. If your child needs a respiratory aid, you should expect help from your doctor and respiratory specialist in the hospital to find community resources in your area and to teach you how to use the equipment properly. BREATHE, the Lung Association, also has qualified personnel to answer questions you may have about respiratory issues.

### **Feeding Pumps**

Under the Children's Enteral Feeding Pump Program, SAIL also pays for feeding pumps and associated supplies for children under age 18; however, nutritional products, nasogastric tubes and gravity feeding bags are not covered. The Therapeutic Nutritional Products Program provides assistance towards the cost of specialized nutritional products for people with complex medical conditions, on a sliding scale based on a number of factors including family income. A physician can order the equipment and forward the request to SaskAbilities (Saskatoon Special Needs Equipment Depot). The feeding pump, feeding bags and an information sheet are sent to you. You can expect that a hospital employee will help you to learn how to use the equipment before you go home with your child. Because the patient is registered on the SAIL Supply System, this allows medical suppliers to invoice SAIL directly for feeding tubes, adapter/extension sets and syringes. If child ages out of the program but still needs a feeding pump, either the Paraplegia program or the Supplementary Health Program may pick up coverage, but coverage will not cease.

### **Adaptive Technology**

Adaptive technology from voice-activated software to eye gaze controlled technology provides a level of autonomy and self-reliance that has a life-changing effect on the lives of people with disabilities. If your child is non-verbal or has other communication issues, your child's education may be enhanced by this technology, and the school may suggest an assessment for adaptive technology. The Ministry of Education may provide a grant for these aids to the school division if they assess the need for this technology for your student. Assessments can be done at SaskAbilities. To apply for coverage for the cost of the device, the school division must demonstrate that the aid must help your child learn in a way that is not possible without the aid. This equipment is on loan for your student, and not owned by the child. SaskAbilities also works on behalf of individuals of all ages to find the adaptive technology that works for them. Saskatchewan residents can access their Adaptive Technology Services on a fee-for-service basis.

## 7.11 INSK Health Passport

The Inclusion Saskatchewan Health Passport is a plain language health care tool for use within Saskatchewan. Developed with the assistance of Inclusion Saskatchewan's ICAN Self-Advocates, the passport is a 4-page fillable form (with accompanying guide) that outlines the essentials about an individual's medical background, care preferences, and ability to consent to health care treatment. The passport can be given to health professionals in both emergency and non-emergency situations. The Health Passport is available via [www.inclusionsk.com/resources](http://www.inclusionsk.com/resources).

## Medical Journal Sample

<b>Date:</b>	<b>Doctor/Specialty:</b>
<b>Office Phone:</b>	<b>Clinic Phone:</b>
<b>Email:</b>	<b>Contact Person:</b>

Reason For Visit: \_\_\_\_\_

\_\_\_\_\_

Symptoms: \_\_\_\_\_

\_\_\_\_\_

Advice Given: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Tests/Medications Prescribed: \_\_\_\_\_

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