



Families as Advocates

Being an advocate for your child

Parenting a child with special needs is not easy. The sooner parents become knowledgeable and strong advocates for their children, the smoother life becomes for their entire family. Although these tips focus on health issues, you can use these ideas at your child's preschool, child care setting, classroom, in the community, and with extended family and neighbours.

Believe with all your heart that your child, like all children, is wonderful – even when she or he gobbles up so much of your time and energy. Tell all the world about this precious gift! Remember, though, that your child with special health care needs is not the heart of your family, but a part of your family.

As soon as possible, **make contact with another family** who also has a child with special needs. Hearing from another parent who never sleeps, feels inadequate and is also frightened about the future will change your life. It may not be easy to talk with a stranger about your child, but it's worth it. The Family Support Social Worker, or another NONA staff member will be more than happy to help you to make connections.

Find out everything that you can about your child's diagnosis from your paediatrician, parent group, local library. NONA staff members are often full of information and resources. The internet has websites full of information for every imaginable diagnosis.

Learn about BC Children's Hospital, Sunny Hill Health Centre, and other pediatric specialists. Ask other parents about their experiences.

Keep records. Request copies of everything. Put this paperwork in one place – in this binder, in a box, or drawer. Here's a list of the kinds of information to gather and/or record:

- **Medical Information:** Include your child's diagnosis, history, immunization records, medications, surgical records, etc. Note what to do in a medical emergency and share this information with your child's babysitter, child care provider, etc.
- **Hospital/clinic records and reports:** You should ask for and keep every piece of paper produced about your child by any health care provider. It is your right to have copies of this information. You can also request written reports from any health care provider (some do charge, however).
- **Personal notes and observations:** Take your own notes every time you talk to your child's doctor, specialist, or other provider. Don't forget to record milestones and achievements.



- **Assistance programs:** Keep up with information about helpful programs that for which your child may be eligible. **Make sure to ask our Family Support Worker about these programs.**
- **School records:** This includes report cards, IEPs, any notes from your school or your notes.
- **Telephone contact notes:** Make notes of phone calls you make or receive about your child.
- **Correspondence:** Keep a copy any time you receive or write a letter regarding your child to a health care provider or school personnel.
- **Expenses/Receipts:** Keep up with this information for tax reimbursement purposes.
- **Meetings and Conferences:** You never know when a brochure, a presentation handout, or your notes might come in handy!

Insist that your entire child's team, from pediatricians to social workers, practice **family centred care**. In other words, they are there to acknowledge and support you as you raise your children in your home and community.

Develop strong partnerships with health and other professionals in your child's life, so that you can work together and use the expertise and skills each of you brings to the care of your child. It's especially helpful to have one professional who knows you, your family and your child very well, and who will advocate with you as a partner.

Know that YOU are your child's best advocate. No one else will do the job as well. Use all the information, contact, friends, and skills you have gathered to practice your advocacy firmly, but with kindness and humour.

Take care of yourself.

(adapted from Family Voices, an American grassroots network of families and friends speaking on behalf of children with special health care needs. www.familyvoices.org)