

# X. Advocacy

## Parents Speaking Up

Our history is replete with inequality and oppression of minorities. For those who have disabilities, their greatest handicap continues to be discrimination.

In the first half of the 20th century, attempts at advocacy for people with disabilities were localized and had little impact on the nation as a whole. At best, they won legal rights that provided limited financial support and public assistance. However, there was no recognition that these people had the same interests and abilities and needs as the mainstream population.

The civil rights movement of the 1960s, though often violent and disturbing, brought the issue of minority rights into everybody's homes. It paved the way for the birth of nationally recognized organizations that have successfully promoted major changes to our laws and to the way society views people with disabilities. Victories include the onset of the Special Olympics in 1968, The Disability Rights Movement in 1970, and changes to the Canadian Charter of Rights and Freedoms in 1981 and the Americans with Disabilities Act in 1990.

Great accomplishments, certainly, but until full inclusion of all people with special needs into schools, communities and the job market becomes the norm, the need for advocacy is not over.

The necessity of advocating for those with intellectual challenges is that, unlike many other minority groups, their limited cognitive ability affects their capability to stand up and speak out for themselves. So, the need for parents, teachers, politicians and community members to become their advocates is critical rather than optional.



### Advocacy has a twofold purpose

First, advocates argue for the protection of the basic **civil rights** of an individual. Second, they **educate others** to certain important principles:

1. People with special needs must be *recognized on the basis of individual merit*; not on stereotyped assumptions;
2. Changes must be incorporated that enables them to *participate more easily in public places and at public events*; and
3. They have the right to, and should be encouraged and helped to *integrate with people who do not have disabilities*.

A child's advocate helps others understand what is unique about that child while removing irrational fears by illuminating the ways he is similar to his peers. The goal is, ultimately, the acceptance of children with Down syndrome on equal terms.

## Advocacy in Education: Parents Still Do It Best

Since the mid 1980s, there have been incredible changes in how children with Down syndrome are educated. Parent advocates have brought about shifts in societal thinking that now give their children more options; an integral one being inclusion in the regular school. Parents may not believe it, but they do have the final say in how their children are educated. But if they do not take an active role in making decisions for their child, others will do it for them and those decisions may be based on a lack of knowledge or an agenda that's contrary to that of the parents.

Most educators shaped their beliefs and perceptions when they were children themselves. Later, in university, there were few – if any – mandatory courses on teaching students with special needs. Special education was a separate degree and teachers had no reason to think they would need a course on inclusion. Since inclusion of students with Down syndrome is still a “first” for most educators, they may see *only* the Down syndrome without the knowledge or insight to appreciate fully the potential of the individual. So, the parents' role as advocates must start with the education of educators and the introduction of others to their child with all his uniqueness.



*Parents are the constant link between child and community.*

Advocacy that promotes sharing information, rather than invoking confrontation, recognizes the reality that people in the community need to be equipped to deal with the challenges that a child with special needs presents. It also assists with dispelling ‘myths’ that are harmful or hamper a child’s ability to reach his potential.

However, in the process of educating others, there is always the potential for misunderstanding and confrontation. Parents may not feel comfortable with their role or may lack the “salesmanship” skills that are sometimes called for. It’s difficult to control one’s emotions while struggling to help others see the child with Down syndrome as a person first. Unintentional or intentional slights have the power to hurt parents, create mistrust and misgivings, and make parents not only start to doubt themselves, but also question their child’s abilities or right to belong. If emotions should heat up and reason becomes threatened, it’s often helpful to look to others for mediation.

Parents are bound to err in the advocacy process because they are human too! Educators must remember that with parenting comes passion, and teachers will often take the brunt of criticism because of their front-line position. They can help keep emotions calm by encouraging regular communication and by maintaining an “open door” policy for their classroom. For issues that cannot be resolved in the classroom, they need to direct parents to school administration. At all times, parents need to feel that their presence in the school is welcome.



## Learning to be an Effective Advocate

Initially, the learning curve for becoming an advocate often feels steep for parents ... as one parent reminded a teacher, “It is a first for me, too!” In their zeal, they immerse themselves in political, educational and health care issues in a relatively short time span.

All of a sudden, others are either looking to them as “the experts” – a responsibility that is overwhelming – or putting a “guilt trip” on them about how their child with Down syndrome requires more funding and more assistance than what they may perceive is his due.

Parents can better withstand criticisms, contend with obstacles and become more effective as advocates by:

- ☑ keeping their knowledge about their child’s disability current;
- ☑ learning about parent rights and responsibilities;
- ☑ attending parent or professional workshops and conferences;
- ☑ belonging to a parent support group;
- ☑ surfing the Internet;
- ☑ observing their child in the classroom regularly;
- ☑ staying active in the school community;
- ☑ participating in the Individual Program Plan (IPP);
- ☑ thanking others for their interest in and support of their child’s education; and
- ☑ learning effective communication/conflict resolution strategies.

## The Money and the Myths

Both money and myths typically impede advocacy. Often, behind these myths is a hidden agenda that has more to do with the unwillingness of bureaucracies to change than what is best for student learning.

**Myth:** *The school does not have the funding to support my child.*

**Reality:** Despite the fact that your child’s school is not given a blank cheque, school jurisdictions do receive block funding that they can designate at their discretion. If inclusion is a part of the philosophy of a school, it will welcome your child.

**Myth:** *My child’s needs are too significant and will interfere with other students’ learning.*

**Reality:** Your child is not the only one with unique learning needs within any regular classroom. Teachers should be ready, willing and able to welcome all learners.

**Myth:** *There are no trained teachers outside of a segregated placement, so my child will learn best in a special-needs classroom.*

**Reality:** Teachers are professionals who are continually accessing professional development opportunities to expand their areas of expertise. As well, teachers are learners like the rest of us! They can gain the needed skills to teach your child effectively.

**Myth:** *The school team alone develops my child's IPP.*

**Reality:** Parents have a critical role in preparing the IPP by contributing relevant, up-to-date information on their child's health, development, home experiences and daily behaviours. To ensure parents feel their input is wanted and valued, teachers and parents need to learn to work together on the team by establishing ground rules for communication at the beginning of the year, inviting open dialogue and encouraging regular face-to-face visits. On completion of the IPP, the parent is asked to sign it indicating that they understand and agree with the educational plan. If they don't agree with the goals or strategies, it's their prerogative to not sign and politely request that the IPP process continue until consensus is reached.

**Myth:** *If I consent to a psychological assessment for my child, I must accept the recommendations.*

**Reality:** Many parents have consented to assessments only to discover that, instead of being used to obtain funding or for program planning as implied, the results were being used as a rationale to place the student in a special education program. Parents are not obliged to accept the recommendations and they do have the liberty to appeal.

## Parents Have the Right to Informed Consent

Parents will eventually be approached with the request to consent to assessment. In this situation, they have the right to advocate for assessments that will benefit their child. To do this, they must also have the time to gather the facts needed to make their decision.

No area of assessment creates more controversy than the issue of intelligence (IQ) testing. The dilemma centres on the negative implications of a low score. On an oddly positive note, a low score ensures the school jurisdiction receives more funding. However, the negative ramification may be a recommendation against inclusion in the regular classroom based on the IQ score. So, it is expected that educators will afford parents sufficient time and background data for them to give informed consent for an assessment.



*Informed consent* is about making a decision based on complete information. That means: taking home the consent form to review with other family members; waiting a day or so to ensure there is no change of mind; and talking to other parents, professionals and caregivers in their personal support network who can share their experiences, provide a rationale and offer emotional and moral support.

*Informed consent* entails safeguarding the best interests of their child by asking lots of questions. Legitimate questions to ask include those about; the procedure, the examiner's qualifications and experience, what test materials measure, the timing of the test and how the results will be interpreted. Parents should be allowed to speak directly with the professional who will be completing the assessment.

*Informed consent* won't necessarily prepare parents for the impact of having their child ascribed a lower, less favourable score.

## Educators Must Respect Client Confidentiality

In the fall, parents sign a consent form that is placed in their child's file. This form typically allows school staff to access information and discuss student progress. However, unless specified, school records cannot be shared with anyone else unless express written consent is obtained from the parents. The consent form must identify to whom information can be released. Failure to abide by this is a breach of ethics and a violation of trust.

During team meetings, information may be shared with team members for the sole purpose of helping them to make decisions that are in the best interest of the student. However, on leaving the meeting it is incumbent that these people not discuss private information (e.g., test scores) with others in the school community (i.e. volunteers, lunchroom supervisor).

## Common Misinformation Given to Parents

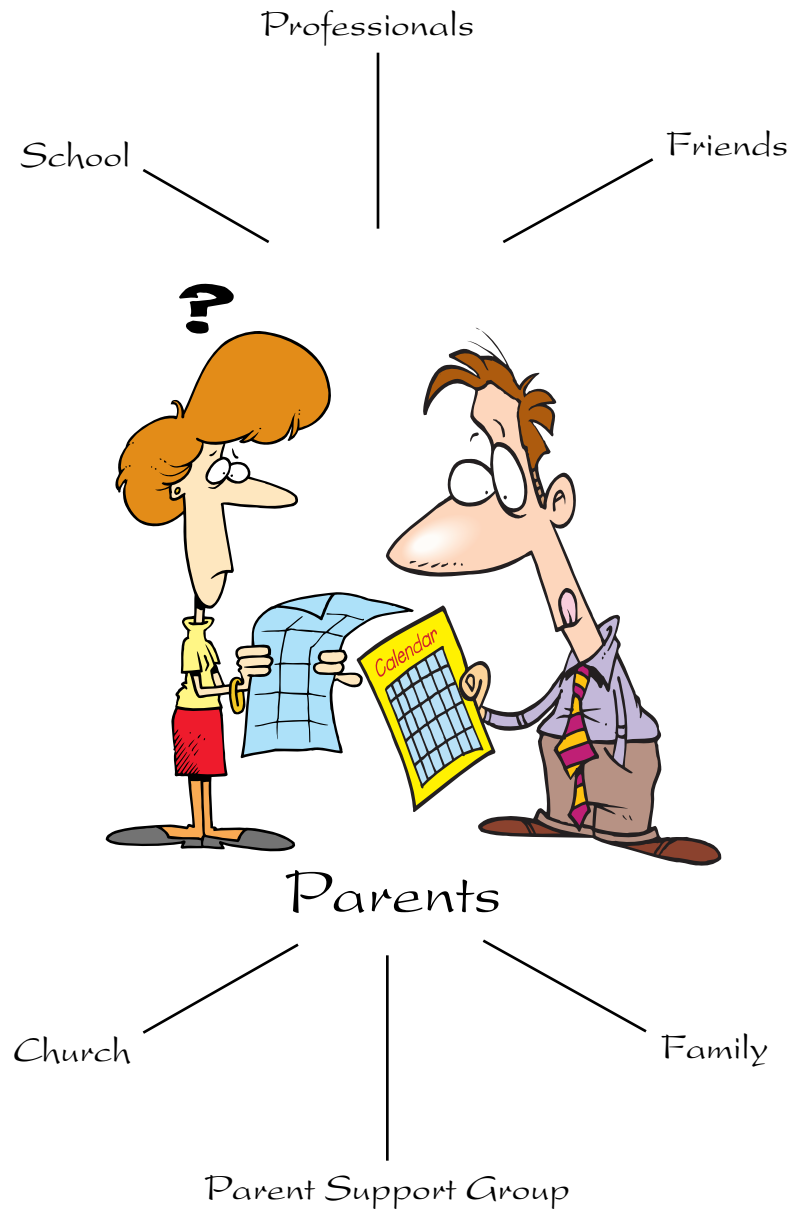
- ⊗ *If parents do not consent to IQ testing, the school won't be able to get the funding needed for education assistant support.* There are other options and there are also many students who don't qualify for funding but who receive education assistant support.
- ⊗ *Without testing, there is no funding for the school.* Standardized testing is only one option; behavioural assessments, IPPs, report cards, letters from doctors and portfolio assessments can be used alongside or instead of standardized testing.
- ⊗ *The results will not be used for placement.* Some educators still make the erroneous assumption that a low IQ score means a child does not belong in the regular classroom.
- ⊗ *Parents are told an IQ score is required to access severe funding and, if the child is not tested, the school won't have sufficient funding for a full-time education assistant.* Students who are not tested should still get the support if there is a needs-based assessment.
- ⊗ *Parents are told that their child must be severely disabled to get funding.* It's important to determine if moderate delays in several areas can qualify the student for severe funding. Parents should also be aware that there is funding available for mild to moderate disabilities. It's not as generous, but schools often "top it up" from other sources.
- ⊗ *Parents are led to believe that their child's school receives funding directly.* The central office typically pools and allocates all mild to moderate and severe funding. Schools can only put in a request.
- ⊗ *Parents assume that the school is giving accurate, up-to-date information about services available within their jurisdiction.* If a school doesn't have resource specialists or experience with students with special needs, advice may be outdated. Check the facts by talking to other parents and phoning the central office.
- ⊗ *School board staff must do the testing.* Parents have the option to engage a psychologist or other professional in private practice. Parents then control when and what – if any – results are released, and to whom the findings are given.



## Investing for the Long Term

Parents can tire in their job of advocating for their child's educational needs. It's common for them to run out of mental and physical energy and feel like "throwing in the towel." No one is invincible.

Each parent has a different breaking point and must be able to identify when it's time to ask extended family, friends and others for help. Parent support groups, professionals and, possibly, personal counseling may be essential to ensure that the parent's mental and physical health are maintained. Just as the child needs a circle of support, so too, do the parents need their circle of support.



Take a break, re-group and hopefully return to the advocacy role re-energized; ready to keep on teaching others what you know about your child.

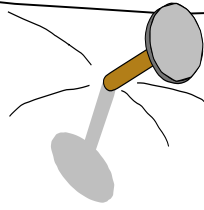
# A Parent's Rights

## A Parent Has the Right To:

- be involved in decisions affecting their child's education;
- be a welcome member of the IPP planning team;
- give written consent for any formal evaluations to be conducted and to only consider evaluations based on sound, verifiable reasons from the school;
- make the decision about placement in any special education program;
- ask for a report on their child's progress during the school year;
- access the information in their child's school files;
- access information on their child from teachers, principals and board administration;
- be fully informed of the programs at the school;
- appeal placement decisions they do not agree with;
- be an informed member of their child's education team.

## Parental Responsibilities Include:

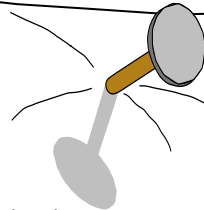
- becoming an effective team member, aware of the fiscal, personnel and other restraints facing the school;
- supporting the teacher and class by advocating for help and additional staff;
- sharing concerns with the teacher;
- establishing ongoing communication between home and school;
- responding quickly to letters, notes, memos and requests;
- sharing relevant, updated information about their child's development, home experiences and daily behaviours. Their observations and suggestions can be a valuable resource to aid their child's progress;
- providing information about their child's medical and developmental progress and updating this information when necessary;
- asking for clarification of any aspect of the program that is unclear;
- learning as much as possible about the school and jurisdiction's policies and regulations;
- gaining information on program options available for their child within the school jurisdiction;
- being information seekers in terms of keeping current on materials, programs and resources that will benefit their child.



**I**nclusion, to me, means to be absolutely accepted in every aspect of community life – school, work, community, etc.

Our son is still very little, so we are not yet dealing with the education system thus we can not comment on how it affects his development. What we can tell you is we treat him like everyone else and we have found people tend to follow our lead.

My child's future, I hope, will be much like all other children growing up and will participate in milestones along the way.



**O**ur son, Greg, wants to grow up, get a job, have an apartment, drive a car and have friends. The same goals as others his age.

We see inclusion as the way to give Greg a chance to fulfil his dreams. In the regular classroom, Greg is challenged academically and is learning how to interact with his peers. We have seen the benefits of inclusion for Greg. Also, in his seven years in his elementary school, we have seen the changes in views of others who did not understand why we would choose inclusion for Greg.

At Greg's elementary school graduation, they offered support and encouragement for Greg's inclusion in Junior High School.