



## Down Syndrome Association of Metropolitan Toronto

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The Down Syndrome Association of Metropolitan Toronto represents approximately 150 families and assumes responsibility to speak to the interests of all persons with Down Syndrome, including the many children and young adults who are wards of the Province and usually living in foster homes, group homes, small and large institutions.

Full participation in the mainstream of Canadian life has been the unspoken and unfulfilled dream of parents of children with Down Syndrome for many generations.

We have struggled to protect our children from pervasive discrimination ranging from the withholding of necessary medical treatment to newborns to the rejection of our children from tiny tots ballet classes. We have struggled to work within social services and education systems which have been rejecting or overly protective, operate from a base of outmoded stereotypes and serve to keep our childrens' lives from the cradle to the grave running parallel to their typical peers but not intersecting with them.

We have fought over the past 30 years to win our childrens' right to education - now we are fighting for full and equal citizenship in Canadian society - integration. This is why we have moved away from seeing our children within a medical model wherein education is treatment, to education is the process of integration - acquiring knowledge, skills, preparing to assume adult work, family and societal responsibilities, and becoming part of the social fabric of the community.

The past two and a half decades have increasingly focused our attention on the fights of various disadvantaged groups, racial, religious, ethnic, to attain their full human and civil rights to participate as equals in the life of their communities.

Handicapped people are among the last disenfranchised groups in Canadian society now challenging us to open the doors.

The Canadian Charter of Rights and Freedoms guarantees

all people "the right to equal protection and equal benefit of the law, without discrimination" including discrimination based on mental or physical disability.

This means that they are therefore entitled to equal benefit of education under the law.

We need only look at pupils labelled Trainable Retarded who have been referred to in the response of the Metropolitan Toronto School Board Special Education Committee on page 28 as being incapable of achieving economic self-sufficiency. Since when is it the responsibility of the school system to make predictions about any pupils' future earning capacity and to use this judgement to determine educational programs? Surely this is an example of not only interference with an individual's legal right to quality education and their right to be prepared to seek competitive employment opportunities but also reflects prejudice and a lack of knowledge of new developments in employment for persons whose needs are very challenging.

Parents today have a heightened perception of civil rights issues and we Canadians are being educated as a society increasingly about the Charter of Rights and Freedoms and the role of the Court as a redressor of wrongs.

As a result, we must therefore question whether segregated education, which leads our children not to full participation in Canadian society which is their right, but to a type of "underworld" of institutions, sheltered workshops and chronic poverty, is really their entitlement to equal benefit of education under the law.

Integrated education is not only a quality education issue, it is a civil and human rights issue. It is a critical determinant of the degree to which children with Down Syndrome grow up to be recipients of service or participating citizens in Ontario receiving benefits under the Law equal to their typical peers.

There are many concerns which the Down Syndrome Association of Metropolitan Toronto has about the policy papers on the Education Act and Regulation 554/81.

- 1). Firstly, we want the government of Ontario and the

Ministry of Education to make a clear commitment to integration of children with special needs into their home school, regular chronologically age appropriate class with programs, services, and personnel provided to meet their needs. This commitment should be part of a Preamble to the amended Act and acknowledge that integration is both an education and civil rights issue.

Therefore, we recommend:

- a). that the Act make an implicit and explicit commitment to the fundamental right of all children with special needs to be educated with their chronologically age appropriate peers in their local school, regular class with individualized programs and services.
- b). that (p. 1 Education Act) I 164a be added - Placement means local school, chronologically age appropriate regular class
- c). that (p. 1 Education Act) I 164b be added - All children, including exceptional pupils, shall be registered to the homeroom teacher in their local school, chronologically age appropriate regular class including those children remaining by parental choice in segregated classes.

#### Identification Placement Review Committee (IPRC)

IPRC's have been the main battleground for parents of children with special needs and most find it a frustrating experience. However, if the following recommendations were adopted, the IPRC's could function with parents as a program planning and monitoring body.

Therefore, we recommend:

- 1). that IPRC become the Identification Program Review Committee as placement is typically assumed to be local school, chronologically age appropriate regular class.
- 2). the child's identification, plan of programs and services, based on a strengths and needs

assessment, should be the task of the IPRC.

- 3). re Part 2 Reg. 554/81, p.2 (4) we recommend-  
"When a committee is engaged in identifying a pupil as exceptional, the committee shall obtain and consider an educational, a strengths and needs assessment of the pupil and additional assessments, documentation or witnesses the parent wishes to provide.
- 4). re (a) (b) we recommend these be deleted as they refer to forced assessments.  
re 4 (f) iii p.3 we suggest:  
"the recommendation in respect of the provision of special education programs and services to the child in the regular chronologically age appropriate classroom setting.

#### Appeal Boards

Appeal Boards are again a difficult experience for parents who often feel they are fighting an uphill battle trying to have their child's needs met, particularly if they want his programs and services delivered in an integrated placement.

Therefore we recommend:

- 1). The right to appeal must remain in the Act itself.
- 2). The Appeal Board must remain a Board, not be downgraded in fact or perception to committee level. Parents do not fear formality - they fear lack of fairness.
- 3). re Reg. 554/81 p. 8, 4(i) (c) we recommend -  
"the placement and programming for the child as an exceptional pupil".
- 4). re Reg. 554/81 p. 9 (6) (1) we recommend -  
"An exceptional pupil's placement, program, and services shall not be made or changed without the written consent of the parent". Therefore, (2)(a)(b) should be deleted.

The composition of Appeal Boards is also a contentious issue and one of the reasons parents often feel they will not get an impartial hearing.

- 1). Therefore, we recommend, in respect of Reg. 554/81, p. 10, (7)(3) that (d) be added: "(d) the Board Chairperson shall be a person with recognized training and/or experience in the mediation of disputes and be agreed upon by the parent or his representative and the representative of the Board".
- 2). re p. 11, (5)(a) we recommend:  
"(a) a member of a local association as defined in clause 182 (1)(c) of the Act or any individual who is nominated by a parent".
- 3). We strongly recommend that the Statutory Powers and Prodedures Act apply to Appeal Board proceedings.

#### Labelling

Labelling is a very destructive process which accomplishes only the setting up of self-fulfilling prophesies, the creation of artificial barriers between people and the perpetuation of prejudice, stereotyping and superstition.

It also is not helpful in determining a pupil's individual strengths and needs and his educational programs and services.

It is sometimes assumed by professionals that parents object to the word "retarded" when referring, for example, to "trainable retarded students". However, while the word retarded is in general seen to be a pejorative term in our society, and one which has many serious and far reaching life consequences should it be attached to you, the terms "trainable" or "educable" as referring to human beings is seen as the more objectionable. One of the most difficult tasks of persons labelled mentally retarded is to have others see them as people first and not as a set of conditions, not as an object of pity, and certainly not as a loveable class of pets down the hall with whom a typical child can to to play, "Can I play with the TR's now, Mrs. Brown?"

We would like to see programming related to a strengths and needs assessment which does not need to be tied to labels. Labels such as trainable retarded, educable mentally retarded, multiply handicapped, tell the teacher nothing about that child's

abilities, strengths, interests and needs. Therefore, the global label "exceptional" is adequate for any child's purpose and must therefore be adequate for the Ministry's purpose in allocating funding in an effective manner.

Removing labels as suggested in the proposed changes should be a real rather than cosmetic change and this can only be effected if the assessment tools are focused around strengths and needs and are label blind.

The Down Syndrome Association has several recommendations to suggest in this area which we feel are not only educationally sound, are in accordance with human and civil rights, but also carry a moral imperative.

Therefore, we recommend:

- 1). re Part 1, The Education Act, p. 1, 21(1) should read: "Exceptional pupil" means a pupil who is enrolled in a school and whose social, health, emotional, behavioral, communicational, intellectual, physical needs are such that he is considered to need special education programs and services.
- 2). re (82)(a): "In respect of programs and services, the Minister shall require School Boards to define the strengths and needs of exceptional pupils and prescribe appropriate programs and services.

#### Segregated Schools for Students Labelled Trainable Retarded

The Metropolitan Toronto School Board Schools for the Mentally Retarded - This function of the Board is a direct infringement of the right of all children, regardless of exceptionality, to education with their peers and to benefit from integrated education as a springboard to integrated and competitive employment, social, and familial opportunities in adult life.

We recommend very strongly that these schools be closed within a 2 year timeline and its students become the responsibility of their local boards, local school, regular chronologically age appropriate class.

We recommend that the Minister establish a Committee to implement this and to recommend how and where the students entitled to be in school until 21 years of age should continue



their education.

Hard to Serve

We recommend the deletion of any reference to Hard to Serve pupils as we do not believe any child should be labelled unable to profit from instruction.

Institutions

The Down Syndrome Association has a great concern for children who are institutionalized and have no power to speak on their own behalf. Children in these institutions are our most fundamentally deprived citizens and most needy of experiences and connections with children and adults out in the community.

Therefore, in respect of:

- 1). Education Act, p. 22, S 159 a (NEW) should read: "Children of school age residing in a centre, facility, home, hospital or institution shall be the responsibility of the local school board and shall be served in the local schools, chronologically age appropriate regular class or if in partially segregated programs, be registered in the regular homeroom class and be the responsibility of the regular homeroom teacher.

However, a board may, with the approval of the Minister, enter into an agreement with a centre, facility, home, hospital, or institution that is approved, licensed, or registered under any Act to conduct an education program in such a centre, facility, home, hospital or institution for those pupils who, on a temporary or ongoing basis, are, for insurmountable reasons, unable to be served in the local schools."

The Down Syndrome Association hopes that the Minister will take into account in formulating new legislative proposals the concerns of our Association and others regarding the integration of children with special needs into their local schools, chronologically age appropriate classes where they can receive special education programs and services within their natural setting.

Money can always be found when the will is present. Money can always be used more creatively - for example, money spent on bussing children out of their neighbourhood to segregated classes could be more profitably spent on aides in the classroom.

There is alot of professional expertise available to help implement quality integration. Integration is not merely mainstreaming or dumping. It is a process involving team planning, support and services around each exceptional child as well as appropriate teacher training, support and discipline, and direction, and monitoring from school administrators.

Integration is an idea whose time has come. It is not going to go away. Surely the convenience and comfort of old methods and concepts cannot come before the needs and rights of children.