

Rights of Low Vision Children and Their Parents

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1. Introduction

This paper will deal with the rights — medical, educational and rehabilitative — of a very special population of children. Children that are “at risk” because of their recognized visual impairment, as

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well as being “at risk” because some of their basic needs are not being met.

Statistics for 1984 indicate that there are over 3,000 legally blind children under age 19 in Canada¹. Pratt² suggested that there are four times as many partially sighted children as there are legally blind. If this is in fact true, there may be as many as 12,000 low vision children in Canada.

Are these children being served in a manner that recognizes the fact that they are first *children with vision* or are they being placed in programs for the visually impaired and being *taught to be “blind”*? Are low vision children part of the “forgotten population”?

Genensky³, himself a partially sighted individual, stated emphatically:

There is nothing wrong with being totally blind, and there is nothing wrong in providing the totally blind with services appropriate for their blindness. It is, however, grossly unfair to regard the partially sighted... as being blind and to offer them services that are appropriate only for the totally or functionally blind. What

the partially sighted need most of all is to be classified differently from the functionally blind. Until this difference is recognized by our government and society, the partially sighted will continue to be neglected.

2. Medical Rights

The most basic right of the low vision child is that of *accurate diagnosis* of the problem. The diagnostic procedures may range from basic vision screening to more complex diagnostic work-ups. This basic right is most evident if the child is thought of as being “visually at risk”⁴. For all children, neonatal and infant screening programs are of prime importance in detecting a vision loss. There should be mandatory vision screening prior to school entrance.

In 1985, Pennock and Shapiro examined the vision screening programs in public schools in British Columbia. This study was a follow-up investigation of a similar study conducted in 1980⁵. The authors found that the majority of the schools still relied on far-point assessment by means of an eye-chart. They concluded:

It is as probable today as it was five years ago that many children with visual anomalies (other than myopia) are not identified in school screening programmes. Thus many children attempt to learn with some discomfort and/or difficulty in classrooms of this province.

The findings of Pennock and Shapiro⁶ are probably representative of Canada as a whole. One exception is in the Province of New Brunswick, where all Grade One children are provided a “modified clinical examination” by optometrists traveling to schools in a mobile vision van. The program found, during the 1984-1985 school year, that 7.8% of the children had visual problems requiring immediate care, and that 14.0% of the children would need to be seen within six to nine months⁷.

Vision assessment for the multihandicapped child is often a neglected area. Cress *et al.*⁸ discussed the need for policies regarding vision screening for this population. They stated that “most states do not include persons with severe handicaps in vision screening programs, even when such screening is mandatory for the nonhandicapped”. Regardless of the individual’s handicap, every person has a right to comprehensive professional eye examinations⁸.

The multihandicapped are difficult to assess, and many ophthalmologists and optometrists have been frustrated by the fact that these children do not respond to the standard testing procedures⁹. However, within the past several years,

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a plethora of articles and books have delineated methods that are applicable for assessing the vision of these special needs children⁹⁻¹⁸.

No child should be considered “untestable”, regardless of age or the multiplicity of the problem. Many children are diagnosed as being “cortically blind”, even though they have not undergone an electrophysiological measure, such as the visually evoked response (VER)¹⁰. Many children have been placed in educational settings “accompanied by inadequate reports giving some indication of visual classification and an unintelligible description of the specific impairment”¹⁷. It is the right of the parent (and teacher) to know the extent of the vision loss. With this information, realistic goals for the child can be set.

Once a diagnosis of the problem has been made, the obvious need for the child is *treatment*. If the vision problem can be ameliorated (e.g. corrective lenses, low vision aids, surgery, etc.) then the

child should be treated by the appropriate individual. If the child cannot be assisted medically, the child should be referred to the appropriate agency.

Too often the attitude of the eye specialist is "nothing can be done". The doctor makes the diagnosis — "your child is blind" — and the child and the parents have to go home and "live with it". I cannot stress enough the importance of further follow-up by those that have training in the fields of rehabilitation and/or education. Referrals should be made as early as possible. Too often the referral comes at the point the child is ready to enter school, at the age of 5 or 6. This is too late. Early intervention is critical, as it plays a significant role in ameliorating the effects of the loss and preventing the occurrence of additional problems (e.g. motor problems, cognitive deficits).

Children being educated in programs designed specifically for the visually impaired are not always provided with the medical intervention they require. Hofstetter¹⁹ examined the visual needs of 60 visually handicapped students in the Indianapolis public school system and at the Indiana School for the Blind — children diagnosed as having a significant visual loss. The students were "known to have at least some light perception and no other grossly disabling handicaps serious enough to prevent the attaining of reliable responses to visual tests". Hofstetter found that 45% of the students could have been helped significantly by special visual aids and rehabilitative guidance. Another 20-40% would probably have gained from such assistance. Only 15% were judged not to have needed assistance by means of optical aids.

Even more alarming were his findings related to routine vision care. Over 40% of the children who were wearing glasses did not have the correct prescription. The refractive error magnitudes exceeded the criteria for referral in conventional school screenings. He stated, "the specially classified group appears to be receiving no better, or even less, vision care than the rank and file school population".

In his concluding remarks, Hofstetter stated "in a very real sense we may be teaching them (i.e. those recognized as being visually impaired) how to be blind rather than how to utilize such residuals of vision as may be at their disposal". Visually impaired children have the right to receive the "specialized visual atten-

tion that is available and capable of enhancing not only their quality of life but also their opportunities to be self-sufficient and self-supporting"¹⁹.

In my work with visually impaired children, I have found that *treatment* — basic treatment — is often not offered to all children in Canada, particularly if they have more than one problem. Many multihandicapped children are denied treatment, (e.g. surgery, corrective lenses, etc.) because of the severity of their handicaps. Ophthalmologists and optometrists must use the same treatment criteria for patients with and without handicaps⁸.

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Many low vision children, both in residential and day schools, could benefit from *referral* to a low vision clinic. However, some clinics will not accept children. If there is not a clinic available locally, geographical distance must not preclude referrals. Ophthalmologists must refer children to clinics run by optometrists, and vice versa. The needs of the child must come first. Too often the parents are not made aware that visual aids may dramatically improve the visual status of their child. If they are told "nothing can be done", they do not know to question the verdict. Eye practitioners must act as advocates for this unique population.

Before a child is seen at the Low Vision Clinic, input from the child's teachers and the child's parents is crucial. Particularly critical is input from the teacher of the visually impaired working with the child, for he/she is knowledgeable about the child's visual abilities and the child's visual needs.

In an "ideal" situation, the examining doctor, or his assistant, would conduct an "on-site" visit to the home, the school or the work place prior to the assessment²⁰. In a more "realistic" situation, the information should be gained through a Clinic Referral Form. Pre-examination information is critical to the successful prescription of a device and

its longtime usage.

For those children that are seen by a Low Vision Clinic, adequate *follow up* must be available. The referring doctor needs a follow up report, but even more important, the parents and the child's teachers need to know the results of the assessment, and if an aid has been prescribed, how the aid should be used²¹. Children are just as likely to suffer from the "top drawer" syndrome²² if adequate follow up is not provided.

Doctors must convey the assessment information, by means of written reports, to the child's teachers and not expect the information to arrive "through some osmotic process" from the parent to the educator²³. Since educational decisions will be made on the basis of the information gained, the evaluation results are "too important to trust to chance"²³. All children seen by a low vision clinic must be followed carefully. As their visual needs change with maturity and the visual demands change over time, a visit to a low vision clinic should not be a "one-shot deal".

Kelleher, in 1979, wrote the following:

It has been well documented... that there is a tremendous lack of comprehensive low vision services throughout the nation. Teachers, counsellors, social workers, and other non-eyecare professionals have begun dispensing low vision aids to visually impaired persons out of frustration at the difficulty of obtaining appropriate low vision services for their clients and students.²⁴

His comments, unfortunately, remain accurate in the mid 1980s. There is an urgent need for more low vision clinics across Canada. There is an urgent need for pediatric low vision specialists to serve these students.

Parents and children have the right to *medical counselling* regarding the condition underlying the vision problem. Many parents and children that I work with do not know the etiology of the eye problem. I have had many parents say to me that their child has had eye surgery — but cannot tell me what the surgery was. Doctors must spend time talking to the parents and to the children — in language that they can understand. Often a simple diagram will help. Parents need to know more than that their child is blind and glasses will not help.

Parents need to know the cause of the eye problem and to know if treatment can

alleviate the problem. They need to know what services are available for their son or daughter, who the service providers are, and how to access the services. They need to be made aware of services not only directly related to the loss of vision, but also those, such as occupational and physical therapy, speech and language training, and audiological assessment, that may be needed by their child. Parents and children need to learn about environmental modifications that may be beneficial and about equipment (both optical and non-optical) that may be appropriate. They also need to know about eligibility criteria for financial

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assistance (e.g. the "blind" pension, income tax reductions).

To be able to provide this information to the parents, ophthalmologists and optometrists must work to become more informed. If eye practitioners are not able to do anything more for the child, their involvement must not end there. They are obligated to refer the children to those persons or agencies that are able to provide further assistance. Eye professionals too often have the attitude "we are interested in vision but have little interest in blindness" — after all, blindness represents failure and no one likes failure²⁵.

Brilliant²⁶ stated that the attitude and the words "nothing more can be done" must be "struck from low vision vocabulary". Freeman²⁷ suggested that there are two ways that the eye professional can approach the low vision child:

First is the image of the "omnipotent practitioner". From high atop the professional mountain, the doctor will lay down the edict as to whether or not the child will see... The other attitude, the one which puts most children at ease, is that the doctor is a helper whose knowledge will aid the child's achievement in the sighted world.

In all provinces there are provincial and/or local educational and rehabilitative services for visually impaired children. The majority of these services

extend from birth to age 21. The programs not only assist in the basic education of the child (i.e. the three Rs) they also provide students with training in a wide variety of compensatory skills — vision stimulation, orientation and mobility, daily living skills, vocational training, to name a few. Ontario, Quebec and the Atlantic Provinces have residential programs for the visually impaired. Some residential schools also have home-based programs for preschool children, school-age and multihandicapped children. In all provinces, the Canadian National Institute for the Blind has regional offices. Many of these offices employ Children and Youth Counsellors and for older children, many of the offices have Employment Counsellors.

Another area of counselling that is often lacking is that of *genetic counselling*. I have students on my caseload that have never been told that their eye problem was genetic in origin. Pagon²⁸ suggested that "each family with a genetic eye disorder needs to be evaluated to determine the specific diagnosis and its mode of inheritance. All individuals at risk in a given family should be examined and counseled". The low vision child has the right to be educated regarding the cause of the vision problem, and how the condition may be passed on to his/her offspring.

Those working with visually impaired individuals, in either the educational setting or a rehabilitative setting, may be in a unique position to provide some assistance. Cross stated:

Personnel employed by agencies and associations for the blind often spend much time with patients and have extensive contact with relatives. Consequently, his emotional rapport may exceed that of the doctor and his patient, and, since counselling and guidance are already part of this relationship, workers among the blind have considerable opportunity and responsibility to ensure that all who can benefit from genetic counselling are advised of its availability.²⁹

3. Educational/Rehabilitative Rights

All low vision children have the right to an *appropriate education*. In Canada, there is no federal equivalent to the American "Education for all Handicapped Children Act" (Public Law 94-142) that ensures educational

services to children regardless of the handicap. Some provinces (e.g. New Brunswick), but not all, have legislation dealing specifically with the education of the blind child. Ontario's Bill 82, the "Education Amendment Act", provides every exceptional pupil in the province, including those that are visually impaired, with access to educational programs. Regardless of where the child lives, the low vision child is entitled to have an education based on sound education philosophy. These programs must be of the highest quality.

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Hill³⁰ examined the quality of programming to visually impaired students attending public day school programs in Canada. She found that on the whole, educational services in Canada were of high quality. In some parts of Canada, educational services to the preschool and/or multihandicapped visually impaired children were weak. There is, however, always room for improvement. Teachers of the visually impaired must continue to strive for excellence.

A *wide continuum of services* must be available for low vision children, designed to meet their unique needs. The various program alternatives, suggested by Bryant³¹ range from self-contained classrooms/programs (i.e., residential schools; local day schools) to consultative programs (i.e., teacher-counsellor/consultant support to regular classroom teachers).

The services must be provided by *well qualified teachers*, with specialized training in working with low vision students. These teachers "need a knowledge base, skills, sensitivity and appreciation of the unique learning styles and needs of visually handicapped students"³².

The low vision student is different from the totally blind student, and, consequently a *unique curriculum* is necessary. Programs designed to meet the needs of the totally blind may not be suitable for the partially sighted (e.g., orientation and mobility programs). The program must meet the educational, social, psychological and emotional needs of the low vision students so that they will be prepared to "make their own

choices as to how and where they will live, work and recreate"³².

In Canada, teachers can obtain preservice training (diploma level) in working with the visually impaired at the University of British Columbia. The University of Western Ontario offers a 3-summer Additional Qualifications program, for teachers in Ontario that are employed to teach the visually impaired. In a study of 104 teachers of the visually impaired working in Canada completed in 1984, it was found that only 46% had specific training in working with the visually impaired at the diploma or degree level³⁰. There is an urgent need to expand the preservice and inservice training options for teachers of the visually impaired in Canada.

Barraga³³ suggested that teacher training programs must "adapt and change the content... to fit the roles performed and the population served". Teachers of the visually impaired are working with more and more students that have significant amounts of residual vision. Consequently, teachers must have specific training to work with low vision students. She stated:

How much attention are we devoting in teacher preparation courses to the 80 or 85 percent of the school-age population that has usable vision? Certainly not 80 to 85 percent of the curriculum. Teachers complain that 60 to 75 percent of the curriculum relates only to blind learners³³.

The increasing emphasis on the use of residual vision (i.e. "vision training" or "vision stimulation"), with both "normal" low vision children and multihandicapped visually impaired students, must be addressed by teacher training programs.

I am aware of only one training program that deals exclusively with services to low vision individuals — the Pennsylvania College of Optometry's Master of Science Degree Program in Vision Rehabilitation. This is a one year program and is designed "to prepare professionals from a wide variety of disciplines (e.g. Optometry, Special Education, Orientation and Mobility, Rehabilitation Teaching, Rehabilitation Counselling and related fields) to employ a team approach in working with low vision individuals"³⁴. There is no such program in Canada.

Low vision children have the right to be provided with all the *necessary equipment* that they need to complete their

schooling and to train them for future employment, along with the right to receive *training* in the proper use of such equipment. The term "equipment" not only refers to optical aids, but also to a wide variety of non-optical aids.

Many children need aids and appliances for both school and home — both should be made available. The financial status of the child's parents should not be a consideration. If the parents are unable to pay for the necessary equipment, and it is not supplied by the educational system, other sources of financial support must be tapped (e.g., service clubs, foundations, insurance companies, etc.). Too often, there are significant delays in obtaining the necessary equipment, due to lack of funding.

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The low vision child and the child's parents have a right to *educational, psychological and vocational counselling* by persons that are trained specifically to provide the necessary assistance. The teacher of the visually impaired is one provider of counselling, however, often the teacher works in conjunction with many other professionals (e.g., guidance counsellors). Teachers of the visually impaired should be cognizant of their own limitations in the area of counselling, and refer their students for further assistance, if appropriate (e.g., psychiatric counselling, vocational counselling, etc.).

In the area of *educational counselling*, the teacher of the visually impaired should be knowledgeable about the educational programs available to the student, in the child's home community. She/he must help the student choose courses that are appropriate for future career goals, must be able to discuss with the student and the student's teachers any modifications and/or adaptations that will be necessary, and must be aware of resources that may assist the student (e.g., reader service, books on tape).

One of the greatest handicaps of being visually impaired is society's lowered expectations of the individual. The teacher of the visually impaired must

provide counselling to students, other teachers, parents, etc., that is realistic and appropriate. Visually impaired students are expected to compete alongside of their sighted peers — visually impaired students should not be getting A's because they are different — they should be getting A's (or B's or C's) because they deserve them.

In the area of *psychological counselling* the teacher of the visually impaired plays a significant role, in her work with both the student and the student's parents. A great deal has been written about the psychological impact of a visual impairment³⁵⁻³⁸. The adjustment of a person to being partially sighted is considered by some to be greater than the adjustment to being totally blind. They are people "in limbo", neither sighted nor blind, the "marginal man"³⁹ often desperately trying to appear "normal". Tuttle stated, "unfortunately, low vision provides the individual with the opportunity to hide his disability, to play "as if" he were fully sighted"³⁸.

The teacher of the low vision student can be a "sounding board" for the child and the child's family (e.g., siblings). The teacher can be instrumental in bringing together visually impaired students so that they can discuss the adjustment problems inherent with low vision. The low vision student, particularly the adolescent student, needs to define and delineate the personal issues intrinsic to being a young adult with low vision. Along with his teacher, Roessing⁴⁰ suggested that the student should explore such issues as: how he differs from peers because of his low vision, if at all; his feelings about the visual impairment and/or physical handicap; if being different equals being inferior or superior to others; how sighted peers perceive him; the issue of driving a car; the attitudes and opinions of his peers with low vision; the opinions expressed by successful blind members of the community about the trials and pleasures of being a low vision person; dating, marriage, family, children; and finally, the work ethic and visual loss.

The teacher of the visually impaired may also be a provider of *vocational counselling* to the low vision student. Guidance counsellors, employment counsellors and rehabilitation counsellors also play a vital role. Career education is an "essential part of every student's education"³⁹. Spungin stated:

I find that many visually handicapped

youngsters do not have an accurate picture of themselves in relation to their peers. Students tend to think either that they can do absolutely anything in a particular field, or that they can do absolutely nothing. Many students seem to be laboring with a serious lack of information regarding their own specific strengths and limitations.³⁹

It is the role of the vision teacher or rehabilitation counsellor to help the student understand the effects of the vision loss in terms of future vocational plans. Does the child's vision loss affect whether or not the job can be done, with modifications, without modifications, or not at all? The days of the "stereotypic" jobs for the visually impaired (such as chair caning, mop making and piano tuning) hopefully are over. Many different opportunities exist in the 1980s. Technology for the visually impaired has opened a lot of doors^{41,42}. The low vision student has a right to be made vocationally productive. The decision regarding a specific occupation must be based on "the capacity of the individual to function efficiently and effectively rather than upon any measured acuity or labeled categorization"⁴³.

The employment prospects for the handicapped unfortunately are bleak, particularly in this time of high unemployment. The partially sighted individual, given proper training, which results in obtaining the necessary qualifications has the right to *employment*. Along with the right to employment are ancillary rights to adequate *housing* and means of *transportation*.

Kirchner and Peterson⁴⁴ examined employment in the blind and visually impaired in the United States. They found that there was widespread unemployment. Approximately 75% of the general adult population is employed, whereas, less than one third of the blind and visually impaired were working. In another study by Kirchner and Peterson⁴⁵ it was found that of those blind and visually impaired persons that were employed, many were underemployed (i.e. working fewer hours than desired or employed in jobs that are not commensurate in status, income or challenge with their training skills and desires).

There have been no comparable studies in Canada that I am aware of. However, it is not unreasonable to expect to find similar statistics. As advocates for the visually impaired, it is our responsi-

bility to promote the hiring of visually impaired individuals, if they are qualified for the job.

4. Summary

In summary, it is apparent that low vision children and their parents have many rights, however, many of their basic rights are not being met by those of us that are working with them. They have health care rights, that must be met by the health professions (i.e., ophthalmologists, optometrists, low vision technicians, etc.). They have *educational rights*, that must be met by the education

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profession (i.e. educators, administrators, counsellors) and they have *rehabilitative rights*, that must be met by rehabilitation agencies (i.e. rehabilitation counsellors, employment counsellors).

There are many professionals who deal with low vision children. Each of us must determine our unique role, and strive to provide the best service available within our mandate. We must be the advocates for those with low vision. They are a unique group. They have unique needs. Our goal should be to make the low vision individual function at his/her highest possible level. However, none of us can "do it alone". We must work together in an interdisciplinary fashion. We must not let low vision children become part of the "forgotten population".

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“Je m'enrichis, mais ma photo ne paraît pas en page couverture de la RCO...”

(nos excuses au groupe du Dr Hook et du spectacle de médecine)

Eh bien, votre photo pourrait paraître en page couverture.

Nous avons publié en page couverture de notre édition du printemps 1987 une photographie réalisée par le Dr Arnold Brown, optométriste de Saint-Jean (Nouveau-Brunswick). Pour le présent numéro, c'est le directeur national des Communications, Michael DiCola, qui est l'auteur de la photo.

Pour les numéros à venir, nous aimerions poursuivre notre présentation en page couverture de photographies produites par les optométristes et le personnel de l'optométrie. Veuillez nous faire parvenir votre photographie favorite en disposition horizontale (c.-à-d. plus large que haute, pour faire sur la couverture de la RCO • CJO), vos diapositives panoramiques en 35 mm, chacune étant accompagnée d'un titre, de votre nom et de votre adresse. En “récompense”, vous aurez droit à une mention d'origine et aurez la satisfaction de contempler votre travail en page couverture de votre journal national.

Les rédacteurs se réservent le droit d'accepter ou de rejeter toute photo soumise.

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