The MIRA Foundation

A LONGETUDINAL STUDY AND PRACTICE ON THE BLIND YOUTH AND THE GUIDE DOG

Noël Champagne, E.D., MA. Psy.; DESAS

Psychologist

Éric St-Pierre, O.C.

President and Chief Executive Officer

&

Robert Viau, Ph. D.

August 2004

Abstract

Since 1990, the MIRA Foundation's major achievement has been to match blind youth with a guide dog, integrating the fields of orientation, mobility, and social integration to the services for blind people.

Removing social and physical barriers, as well as dealing with the professionals' concerns has been achieved. The guide dog is not a panacea to the disability or to the life conditions of blind youth. The process of matching a blind adolescent with a guide dog must be based on the youth and his family, and in close collaboration with other specialists and educators throughout the process.

What follows is a description of the blind youth and guide dog program. It also provides future direction concerning international services.

Introduction

Since the last century, the comprehension of the mobility of a blind person has evolved significantly. Many schools opened their doors, mainly in the U.S.A., such as institutions for the training and use of white canes and schools for training and using guide dogs. Guide dog training schools also appeared in England and in Australia. During the 1980s, new research and intervention practices were developed in the areas of adaptation and rehabilitation for people with a visual impairment. Many American Universities developed orientation and mobility training programs for specialists to work with the visually impaired.

A guide dog school in Quebec

Traditionally, rehabilitation centres and guide dog training schools developed concurrently. The partnership between the MIRA Foundation and the *Institut Nazareth et Louis Braille* (a rehabilitation centre for the visually impaired) is a first in North America in this particular field. And another first is creating a guide dog training program for the blind youth (Champagne N., 2000).

The MIRA Foundation in Quebec starts operating in 1981. It innovates in introducing in its practice the teaching of orientation and mobility while at the same time, the use of a guide dog. The innovation lies in the process of matching the young blind person and a guide dog. Indeed, the blind person will be in close contact with a dog trainer, and with a specialist in orientation and mobility, from the time of the request, through to the selection of the dog, to class participation, to the regular (or on request) follow-up. So, between 1981 and August 2004, 724 guide dogs were matched with blind people.

Insert Figure 1

The Blind Youth and the Guide Dog Program

A new practice in intervention and research started in 1990. The innovation lies on the attribution of guide dogs to blind youth. The creation of a research and intervention strategy to better understand the role of the dog in the life of a blind child has evolved into a program of guide dogs for blind youth, based on the standards and criteria already in place for adults since 1981 (Champagne, N., St-Pierre, É, 1992, 2000). So, between 1991 and August 2004, 36 young blind under the age of 16 lived the experience of moving in the world with a guide dog.

Insert Figure 2

Description of the blind youth and guide dog program

The program, by its nature, is based essentially on the mobility skills and aptitudes of the blind youth. The child, the family, friends, trainers and orientation and mobility specialists, as well as the health care, the social and the educational professionals, all are associated to the process. The program informs and raises awareness (of) the general public about the mobility of blind youth in urban settings, by means of promotional campaigns on road safety. Finally, the program takes its lead from the policies and social practices that are centred on the youth and on community integration.

Insert Table 1

1. The Youth

Started in 1991, the program is offered during summer months (July to mid-August) for secondary school age adolescents and more specifically to those 16 and younger. About the participants: the youngest participant was 10 years old and the older was 15 years old. The mode and the median age were 14 years old. The age average was 13,42 (1,42) years old. The coefficient of variation was 10,60% that means the age distribution was homogenous. All were totally blind, either from the consequence of cancer (retinoblastoma) or of a hereditary disease. One youth was deaf-blind.

Insert Figure 3

2. The Parents

Parent participation is crucial in the process of acquiring a guide dog. The younger the youth, the more parents need to be involved. Parents are invited to information meetings; they are encouraged to observe their son or daughter using a guide dog. Certain parents stayed on site to better understand all the elements related to the use of a guide dog and to orientation on a daily basis. Parent participation was found to be a major factor in the successful outcome of the program. When parents are part of the team, informed and supported through the process there is a better chance of success for integration into the school or recreational environment.

Parents were also welcome to field-sessions after class, with the trainer and the mobility and orientation specialist. These sessions become a training ground for the child, the parents and the practitioners. In this way, the parent's role toward his child was well channelled and the practitioner's role in the life of the youth, well focused.

Parents are privileged partners. They live with the child day-to-day and can intervene in activities when required.

Their actions encourage the child to keep-up the dog-assisted orientation and mobility objectives. The parents gain knowledge on their child and can positively influence their development. They are often called upon to advocate on behalf of the youth, because of the scarcity of resources in the area of rights.

3. Youth Development

This aspect is enticing and fascinating, as it deals with adolescence. The physical and the social maturation are important factors to be considered. Future development has to be taken under consideration at the time of attribution and the evolving use of the dog: height, weight, walking rhythm at the time of acquisition of the dog, keeping in mind the future development of the child.

Based on the MIRA Foundation's experience, there is no difference between boys and girls. Obvious comments or truisms could be made, such as "girls have better learning skills than boys", "girls are more responsible than boys", " boys are more turbulent than girls". However, it would be difficult to attempt to establish a difference between boys and girls who are blind at this stage. In our estimation, blind youth are the same as other youth in the same age group. On the other hand, the fact that the mode and the median age are 14 years old, is not proof that this is the ideal age to obtain a guide dog.

It is important to underline the major contribution of the dog in the social development of the child. As a parent said abruptly "it's better cruising with a guide dog". The impact on social relations and the prevention of isolation are important factors. Finally, the dog's contribution in the emotional life of the child appears to be important, but remains to be proven.

4. Spatial Representation

Spatial representation by a blind person is difficult to analyse. On one hand, what is the image of space for a blind person? How does the blind person "see" an intersection with traffic lights? How does the blind person use past vision? The detection and indicators of the absence of representation of space remain to be established by tests and experiences with blind person in the context of orientation and mobility; but usually we live in a single case situation, N=1.

Individual adaptation strategies, developed by the blind child, to orient himself and to represent space are remarkable. However, in the process of matching, it is better in order to determine the incapacity related to orientation in space.

The use of a guide dog by a youth or by an adult who has no spatial representation is a dangerous and risky proposition. Being a social creature, the dog quickly discovers that there is nothing better than to gently deviate from the path, to go smell a fellow creature, diagonally across the street.

5. Human Resources

The MIRA Foundation's training school includes two instructors, a specialist in orientation and mobility from the Institut Nazareth et Louis Braille (in the partnership agreement) and a psychologist, for a class of six youth. An occupational therapist acts as a consultant for positioning. A coordinating and a maintenance staff round up the human resources team.

6. Youth, Selection and Evaluation Process

In Québec, there are different mechanisms for referral, selection and evaluation of blind youth. As an example, the four young people of the class of 1991, were selected based on their participation in the 1990 research program. However, in general, the referral comes from the rehabilitation centres or from the parents themselves. Once the request is completed, blind youth are evaluated based on their functional ability on site at the school of guide dogs and at different traffic settings close by. The decision to accept a child into the program is based on a consensus reached by the trainers, the orientation and mobility specialist, the referral specialist, the youth and the parents.

Some youth "were on call" which meant a week-long stay, trying-out a guide dog and participating in orientation and mobility training classes. An intervention plan is developed during the year to prepare the youth to participate in the next class, once the skills are mastered.

7. Guide dogs

In the context of establishing the Program, the selection and training of the dog is of the outmost importance. Labradors, Bernese Mountain Dogs and Labernese are the chosen breeds. The last variety, the Labernese, is a cross between a Labrador and a Bernese Mountain Dog. The school has its own breeding program and controls reproduction. Dogs are highly selected by evaluation methods based on health, temperament and training. Dog training is also based on methods established over the last 20 years. Research activities are on-going into the dogs' health and more precisely on hip dysplasia.

8. The Intervention Site

During the program, thirteen classes were held in Québec and New Brunswick, Canada, and two in France. The Québec school site is the best equipped and convenient facility. Ten youth reside at the site at the same time. The environment is barrier-free to facilitate the adolescent's mobility and the control provides a more appropriate learning environment, for the use of a guide dog. Over the years, participation in the endeavour from the surrounding community has grown. This aspect has played an important role in facilitating the youth's apprenticeship with the guide dog.

9. The Class

As in the adult program, the class runs for 30 days. Youth stay on the site. The average class is of 6 teens. Orientation training with the guide dog goes from 8:30 a.m. to 5 p.m., including meal breaks. Class activities are held either in group settings or individually. A youth receives approximately three hours of direct intervention a day. The rhythm of the class progresses from simple to complex. During the four weeks, adolescents learn to know their animal and how to interact. Gradually, they build on their dog skill, from moving within a controlled outside environment and on to a more difficult environment such as a city centre with a large population and with heavy traffic. The education method is based on humour and play. The objective is not to make the adolescent into a "model child" or to reproduce the class room context. Staff must always remember that they are dealing with an adolescent. Youth want to play, laugh, have fun and they learn much better in that environment. Finally, class activities are held in the field. So the learning activities are not passive, but oriented toward action, real-life situations and decision making.

10. The Youth, the Dog, the Practitioners and Others

Once class is over, the youth person and his guide dog return to daily activities: family, school, ongoing orientation and mobility training, friends and social life. The youth is the only master of his guide dog, which he has worked very hard to accomplish. Help on the outside is provided through staff support and follow-up with the youth immediately after class is finished. Eventually, follow-up will be on a regular basis or as needed.

Ultimately, what becomes terribly demanding for the adolescent and for service providers, is the behaviour of Others. The dog attracts others and the youth must continually impress upon them that "He" alone is the driver. Informing others of the "do's" and "don'ts" concerning the use of a guide dog becomes continuous repetition.

Authorities (teachers, practitioners) often get into the act as well of the "lookingafter-the-dog- business"; they tell the youth how to behave toward the dog or read into the youth-dog relationship. At the risk of repeating ourselves, the guide dog is at the exclusive call of his young master who is the only one competent in this relationship. The adolescent will suffer much more from his relations with Others, who are longing-for-a-dog, and who give themselves a dog-gannet-hard-time of telling the teen about the dog-youth relationship, of which they know little or nothing about. The dog attracts and can distract practitioners and others from objectives or from the true reason of their relationship with the adolescent.

Conclusion

The application of a guide dog program for the blind youth is a major innovation in the field. The guide dog, for a teen, is a precious aid to mobility, but is not a panacea to the disability and to the social conditions in which he lives. Experience confirms that the selection, evaluation, matching and follow-up are the keys to success. If the adolescent is completely blind with a clear diagnostic, without other associated disabilities, without further health complications, a "good-good" dog, good parents, a harmonious family life, a good trainer, a good orientation and mobility specialist that's knows the child and the dog well, results will be good. Usually, life is not a quiet river.

Guide dogs represent an aid to mobility which is very different from the use of a cane. Fundamentally, the inherent regulations mechanisms of the apprenticeship of the cane are tactile where as the ones related to the mobility with a guide dog are *proprioceptive*. The guide dog represents a mobility aid very different from the cane. The use of a guide dog requires skill and specific abilities for the blind person. This is why future research on the guide dog and blind youth are considered notably in the spatial orientation, on evaluation methods, dogs' temperament and health.

Also research strategies must be put in place in the community to help the integration of the blind youth. This is a priority since the disparity of resources from one region to another, from one country to another.

References

Champagne, N. (2000), collaboration's story between MIRA and the Nazareth Louis Braille Institute. http://www.mira.ca/contenta/AP1-9-1a.html

Champagne, N, St-Pierre, E. (1992 Juillet), une première sur le rôle du chien dans la vie de l'enfant qui présente une déficience visuelle : stratégies de recherche, une classe de chien-guide et perspectives de développement . Conférence présentée au sixième congrès international sur les relations entre les animaux et nous, Montréal.

http://www.mira.ca/txtpdf/conf_rence_92.pdf

Champagne, N. ; St-Pierre, É., (2000).Mastering time and space : blind youth and their guide dog. <u>http://www.mira.ca/mastering</u>

St-Pierre, É. (1996). <u>Guide dog for the young blind: a program in application in Quebec</u>. Conference presented for the Association for Education and Rehabilitation of the blind and visually impaired (AER), St-Louis, Missouri, USA.

St-Pierre, É. (2003, décembre). <u>Visually handicapped children and guide dogs</u>. Conference presented at the AER Orientation and mobility Division, New-Orleans, Louisiana, USA.



Figure 1. Cumulative record of the number of attributions of guide dog (1981-2004)



Figure 2. Cumulative record of the number of attributions of guide dog for blind youth (1991-2004)

YEAR	Subject	AGE	Sex	PATHOLOGY	REGION
1991	1	12	М	Retinoblastoma	Québec
	2	14	F	Tumor	Québec
	3	14	М	Retinoblastoma	Québec
1992	4	15	М	Retina detachment	Québec
	5	14	F	Glaucoma	Québec
	6	13	F	Retinoblastoma	Québec
1993	7	14	М	Fibroplasis retrolental	France
	8	13	F	Glaucoma	Québec
	9	12	М	Retinoblastoma	Québec
1994	10	13	F	Glaucoma	France
	11	15	F	Fibroplasis retrolental	NewBrunswick
1995	12	10	М	Retinitis pigmentosa	France
	13	14	F	Glaucoma	Ontario
	14	14	F	Anaphtolmia	Québec
1996	15	14	М	Leber's congenital Amaurosis	Québec
	16	14	М	Leber's congenital Amaurosis	Québec
	17	15	F	Leber's congenital Amaurosis	Québec
	18	14	М	Retinoblastoma	France
1997	19	14	М	Tumor	Québec
	20	12	F	Retinitis pigmentosa	Québec
	21	11	F	Glaucoma	Ontario
	22	15	М	Leber's congenital Amaurosis	France
1998	23	15	F	Retinitis pigmentosa	Québec
	24	11	М	Retinoblastoma	Québec
	25	14	F	Leber's congenital Amaurosis	Ontario
1999	26	11	М	Leucemia	Québec
	27	13	М	Premature	Mexico
				Retinopathy	
2001	28	14	М	Leber's congenital Amaurosis	Ontario
	29	15	F	Alstrom Syndrome	New-Brunswick
	30	12	М	Glaucoma	Ontario
2002	31	15	F	Amaurosis	Québec
	32	13	F	Leber's congenital Amaurosis	Ontario
2003	33	13	F	Glaucoma	USA
	34	15	F	Retinoblastoma	France
2004	35	15	М	Micro-ophtalmia	Spain
	36	11	М	Tumor	USA

Table 1.Descriptive chart of the participants in the blind youth and guide
dog program (1991 - August 2004)



Figure 3. Age and number of attributions