

The Educator



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INDEPENDENCE



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The International Council for Education of
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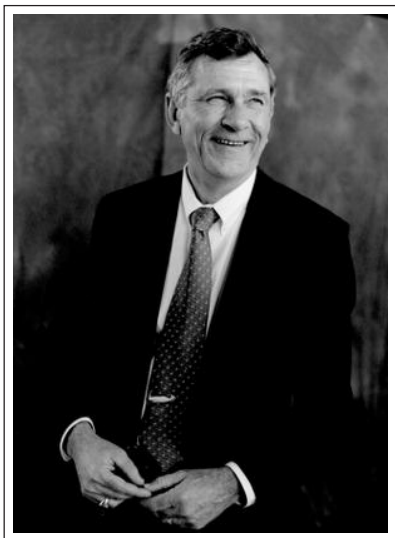
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www.icevi.org

This issue of The Educator is dedicated to the memory of our friend and colleague

Mike Collins

Member of the Executive Committee of ICEVI



Michael T. Collins

1947-2008

As I struggle to find the words to begin this tribute to Mike Collins the words *quiet*, *humble* and *passionate* are the ones that most frequently come to mind.

On May 16, ICEVI and the blind and deafblind children of the world lost a passionate advocate. Those of us who serve on the ICEVI Executive Committee lost a great and wise friend.

I had the privilege of knowing and working with Mike in a number of capacities for more than 30 years. Over that span of time while Mike's professional responsibilities changed several times; what never changed was Mike's passion for the blind and deafblind children to whom he devoted his life.

Whether you met Mike, in a classroom at Perkins, a conference of professionals in the United States or in a remote rural village in the developing world you could always count on three things; -Mike's quiet and calming presence, -his infectious sense of humor and -his great passion for doing whatever needed to be done to assure that blind and deafblind children and their families, everywhere they lived, received the services and support that are their basic human right.

To Mike's wife Linda, his children and his colleagues at Perkins, the ICEVI international family extends our deep condolences. All of us who had the privilege of knowing and working with Mike are better for having had the opportunity "walk a mile" with him.

Rest in peace, Mike!

- Larry Campbell, President, ICEVI

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CONTENTS

1. Message from the President	3
2. Message from the Editor	5
3. Message from the Guest Editor	6
4. ICEVI Executive Committee - Strategic Update	7
5. EFA-VI News	8
7. Update from the World Blind Union	10
8. Children and young adults with visual disabilities: ONCE work models to ensure an independent life – Maria Angeles Matey Garcia	12
9. When Ali goes blind: About disability and the meeting of cultures – Lykke Jensen	17
10. Independent Living – June Waugh	21
11. Spatial Intelligence: The art of adapting the surroundings and their permanent changes to be able to move around safely and successfully – José Nery Picado Segura	25
12. Independence, Education and Technology: An inevitable formula of the future – Victor Tsaran	28
13. Special Interest Group - Education of persons with Batten disease – Bengt Elmerskog	31
14. Consciousness of educated people on their attitude towards disability – A step towards Independence – J.P. Singh	33
15. Parents' Column	40
16. Report from Deafblind International	44

Guest Editor : **Peter Rodney**



Dear Colleagues,

The July issue of *The Educator* marks the mid-point of the current quadrennium, a good time to look at where we are on that “race for educational equity” that I spoke of in my president’s address at the 12th World Conference two years ago.

As predicted, the race has not been particularly easy with lots of uphill terrain during the early stages of the race and as expected more than a few days of bad weather. However, we have been able to follow the race plan that our “coaches” on the Global Task Force set and have passed most of those “mile markers” on time.

The Resource Mobilization Committee recently finalized a Business Plan that was approved by the Global Task Force and the Executive Committee at their April meetings in Hanoi. Establishing equilibrium between the desire of countries to move ahead with their national plans and securing the technical financial resources to do that has, and will continue to be an ongoing challenge. However, the international blindness community is exhibiting a remarkable spirit of solidarity and is working hand-in-hand to explore joint funding opportunities to support the EFA-VI Global Campaign. In October, ICEVI, the WBU and four of its partners (cbm, FOAL, ONCE and Perkins) will meet in Madrid to develop a joint funding

strategy for the EFA-VI program in Latin America. If the results of this effort are positive we hope to replicate such collaborative funding approaches in other regions.

As this issue of *The Educator* goes to press we are pleased to report that the EFA-VI Global Campaign is fully underway in four countries in East Asia, Latin America and West Asia with plans now being finalized in additional countries. At this point in the race the Latin American team, under the leadership of Lucia Piccione, is off to a very fast start and setting a pace that is providing a friendly but serious challenge to other regional teams. As we move ahead to the next stage of the race we anticipate significant progress in the Africa region with a full-time EFA-VI regional coordinator in place by October. Recent reports from Frances Gentle and her Pacific team indicate that they have some fine runners on the course who plan to mount a serious challenge from “down under”.

Our partnerships with the World Blind Union (WBU) and the International Agency for the Prevention of Blindness (IAPB) are being strengthened at both the regional and national levels. Dr. Mani and I will be in Geneva for the WBU General Assembly in August and Dr. Jill Keefe and I will be in Buenos Aires for the IAPB General Assembly later that same month to further strengthen and expand our relationships with

these partners. ICEVI is currently engaged in serious discussions with Deafblind International to assure that the needs of children with deafblindness are not overlooked within the Global Campaign.

The Global Task Force has created a group to explore the development of one or more international distribution centers for high quality-low cost educational materials and the ICEVI Secretariat is now working on a series of simple “guide books” for parents and regular classroom teachers. We anticipate that these developments combined with the recently ratified Convention on the Rights of Persons with Disabilities and the increasingly active involvement of organizations of parents and the national affiliates of the World Blind Union will, in the months ahead, significantly increase the pace of regional and national teams entered in this race for educational equity.

As with all such long races the news is not always good. In May we lost Mike Collins, one of our finest “coaches and runners” to a battle with cancer. In Mike’s memory we dedicate this issue of The Educator.

Another of our most skilled “coaches and runners” Peter Ackland will be leaving his post at Sight Savers

International to join IAPB. I want to use this opportunity to thank Peter for all he has done to get this Global Campaign rolling and to also let him know we hope we can find ways to keep him involved in this “race”.

The finish line is not yet in sight, and we know there are many twists and turns and steep hills ahead. However, the advice from Dr. Mani, our EFA-VI Race Coordinator at our Secretariat in India, is positive.

Let me end this message with a question to you. Are you a runner or an observer? If you are not a runner in this race for educational equity please join us in this race. Get in touch with your regional team leader, put on your running shoes and don’t stop running until every visually impaired child in your country has access to a quality education.

THAT IS THE FINISH LINE!

As always,



Larry Campbell

President



Stockholm, Sweden
July 2008

Dear Reader,

As *The Educator* is published only twice a year you should turn to the website www.icevi.org for the latest information.

The present issue of *The Educator* is the third one having a thematic content. After issues dealing with low vision and self-esteem it is now time to explore the concept *independence*. In the January 2008 issue of *The Educator* I had the great pleasure to introduce to you Peter Rodney from Denmark. I am most happy that Peter once again accepted to be the guest editor.

This time Peter is presenting seven articles written by authors living in six different countries. As you will see independence is a concept with many faces. Independence is also a concept that cannot be separated from the cultural and social environment.

In 2009 we will focus on Braille in January and Literacy in July with Dr Cay Holbrook, Canada, as the guest editor. I am sure that Cay would love to hear from you as soon as possible. Please send her suggestions for articles and authors you think could be proper with regard to the topics mentioned above.

As the editor and holder of the publications portfolio I am always interested to have your comments and suggestions regarding *The Educator*, our website or any other publications published by ICEVI.

Please observe that I have a new e-mail address (harry.svensson@spsm.se). A major reorganization of support to students with special needs is in place in Sweden this summer and all support is now handled by one single agency, the National Agency for Special Needs Education and Schools.

Sincerely,

Harry Svensson

Editor

The idea of Independent Living is central in the process of education and rehabilitation of visually impaired persons



It is my hope that this issue of *The Educator*, with the variety of input on Independent Living, will help to shed light on this important field in the education and rehabilitation of people with visual impairment.

Independent living is a key concept but it does pose problems. The danger is that it is understood as a requirement to live on one's own. For me it is important to underline that Independent Living must always be seen in a social context. But here, cultural differences play an important role. In some societies, it is considered the family's responsibility to take care of persons with impairments. In the Western part of the world, we tend to leave that responsibility to specialised institutions or other public services. This can cause conflicts in the way that Independent Living is practiced. In her article, Lykke Jensen describes a situation where the brother of a young blind person is confused by the implications of the rehabilitation process and asks, "Does that mean I may not help my brother anymore?"

Thus, the overall goal of the rehabilitation process should always be seen in that cultural light.

In a similar contextual approach, our services must always be based on the needs of the visually impaired person. Our methods and professional skills must never form or shape the specific services or approach to the visually impaired person. We must adjust our strategies or methods to the needs of the visually impaired person. If we approach the visually impaired person with fixed ideas about how or in what way the person

should be independent, we will be making a mistake. I heard a wonderful story the other day:

An orientation and mobility instructor was visiting an elderly blind lady and asked if she had any specific needs? The lady responded that it would be nice if she could decide what should be in her own refrigerator herself, instead of the community service choosing for her. The O&M instructor rehearsed the route to the nearest supermarket with her several times and told her that she would be back in two weeks' time to see how things were going.

The instructor returned as promised, and they both looked in the refrigerator and saw all the things the lady liked. Very pleased, the instructor asked, "Now tell me, what do you do when you need groceries?"

"Well," said the lady, "I take my white cane and I tap on the ceiling, then Jensen, who lives in the flat above, knows that I need groceries. He comes down, and we talk a little, and then he goes to the supermarket for me. Afterwards, we have a talk about old times."

It is difficult to judge whether the instructor felt that her training was a success or a failure, but the lady did accomplish two key goals in her present life: the need for groceries and the need for social interaction.

Was this Independent Living? I don't know, but her life had improved a little.

I would very much like to thank the authors of this issue of "The Educator" for their contributions.

Peter Rodney

Guest Editor

ICEVI EXECUTIVE COMMITTEE (EXCO)

- *Strategic Update*

The Executive Committee meeting of the ICEVI, which was held in Hanoi on 9-10 April 2008 resolved some of the key issues, which are presented below for our readers:

1. The Executive Committee reiterated the need to forge collaboration with all stakeholders to make the EFA-VI campaign successful at the national level.
2. It was resolved to identify potential opportunities to promote the EFA-VI campaign in Francophone Africa.
3. The Bicentennial celebrations of Louis Braille must be used as an opportunity to draw the attention of heads of governments and international bodies to the education of children with visual impairment.
4. A Finance Committee with the Treasurer of ICEVI as its Chair has been formed.
5. In order to encourage more individuals and organisations become members of ICEVI, the EXCO resolved that the regions can come up with region specific membership criteria which should be approved by the ICEVI EXCO before commencing implementation.
6. It was resolved to ask the Membership Committee to suggest fresh guidelines for various categories of membership of ICEVI such as individual members, institutional members, international partners, and corporate members.
7. Each organisation represented on the ICEVI EXCO was asked to suggest three names of individuals, foundations or corporations that could be approached as part of the resource mobilization efforts.
8. The EXCO appreciated the progress of the Higher Education project for students with visual impairment being implemented in Indonesia, the Philippines, and Vietnam.
9. Members discussed the background document prepared by Hans Welling, Regional Chair, Europe to expand the mandate of ICEVI to include adult rehabilitation. It was unanimously agreed that, while ICEVI was not ready to make formal arrangements to expand its current mandate to bring rehabilitation workers within its scope, it should not set its face against such developments happening spontaneously and was happy for regional chairs to explore closer relationships with the rehabilitation profession.
10. Members suggested that a search engine option should be included on the ICEVI website to allow for easy access to resources.
11. The proposal to move Tajikistan from the West Asia to the Europe region was discussed. Based on the recommendations of the regional chairs of West Asia and Europe, it was unanimously agreed that Tajikistan should remain in the West Asia region but that Tajikistan should feel free to interact with both ICEVI regional chairpersons and that nothing precluded ICEVI Europe from responding to requests for technical and/or material assistance from Tajikistan.
12. The EXCO unanimously agreed that ICEVI should formally explore with WBU, IAPB and, possibly DbI the development of what has been referred to as a Vision Alliance. The principal officers have been given the authority to enter into those discussions and will report back to the EXCO meeting in November 2008. The EXCO felt it was premature to consider conducting joint world conferences at this time.



EFA-VI NEWS

The Global Task Force (GTF) Meeting

A meeting of the Global Task Force of the EFA-VI campaign was held in Hanoi on 7-8 April 2008. Besides reviewing the progress of the campaign, the GTF included Pakistan and Nepal as the new focus countries in addition to the existing three countries namely Dominican Republic, Paraguay and Vietnam. The GTF approved a comprehensive Business Plan for mobilising resources for the campaign and also suggested appropriate mechanism for documenting the impact of the campaign through short-term documentation and by conducting long-term impact oriented research studies.



EFA-VI meeting with Partners in Vietnam

The Executive Committee of ICEVI had an interactive workshop on 9 April 2008 with the representatives of organisations who work with persons with disabilities in Vietnam. Dr. Nguyen Ngoc Hung, Deputy Director General of the Ministry of External Affairs dealing with international organisations, and Dr. Nguyen Loc, Director of the National Institute of Educational Strategy and Curriculums at the Ministry of

Education and Training attended the workshop. Larry Campbell, President ICEVI gave an overview of the chronological development of ICEVI and the purpose of the EFA-VI campaign. Dr. Minh provided a detailed account of the progress of the EFA-VI campaign in Vietnam. He said that 7,149 children with visual impairment had already been identified for various interventions and added that the objective of the campaign in Vietnam was to provide educational opportunities to 70% of the population of children with visual impairment by 2010 and 100% by 2015. Dr. Mani, Executive Director of the campaign moderated the discussions and summarized the recommendations. The Vietnam experience reveals the commitment of the government to working closely with the national and international organisations involved in the area of disability, and this approach needs to be emulated in other places, observed the participants. The workshop provided an opportunity to the members of the executive committee of ICEVI to see the impact of the global campaign on making a difference in the lives of thousands of children with visual impairment worldwide.



Applications received for the post of the EFA-VI Regional Coordinator for Africa

ICEVI advertised the position of regional coordinator for the EFA-VI campaign in Africa. Applications for the post have been received from Kenya, Nigeria, The Gambia, Malawi, Uganda, India and the Philippines. A selection committee is currently short-listing the applicants for interviews, which will be held by September 2008. The Regional Secretariat will be established at the Africa Union of the Blind (AfUB) and the regional coordinator is expected to assume duty by December 2008. With the availability of this full-time coordinator, the EFA-VI in the Africa region will be off to a good start.

EFA-VI Fiji Forum

A workshop on education for all children with visual impairment (EFA-VI) will be organised jointly by the ICEVI and the World Blind Union of the Pacific region in Suva, Fiji on 6-8 October 2008. The Forum will finalise a national plan for the implementation of the campaign in Fiji. Fiji is expected to be the first focus country in the Pacific region and its success will help a great deal in expanding the campaign activities to other parts of the region.

ICEVI-NIPPON Higher Education Projects

The higher education project of ICEVI supported by the Nippon Foundation has been extended to the Philippines, Vietnam, and Surabaya and Makasar in Indonesia from 2008. A technology centre under the aegis of this project is functioning at the Vietnam Blind Association (VBA) premises. The students who make use of this centre pursue higher education in different disciplines such as journalism, law, psychology, information and communication technology, etc. Similar technology centres are functioning in Ho Chi Minh

City (Vietnam), Manila (the Philippines), Makasar and Surabaya (Indonesia). ICEVI is happy that this project is contributing to the development of leaders among persons with visual impairment, who, in fact can motivate parents and youth with visual impairment to value education as an investment in human capital.



EFA-VI workshops in India

The EFA-VI workshops at the state and regional level are going on full speed in India. The South Asia Regional Office (South) of cbm is supporting the activities in collaboration with the ICEVI West Asia region. Workshops were conducted in the Indian cities of Kolkata, Ahmedabad, Bhopal, Bhubneshwar, Lucknow, and Bengaluru and many more workshops are in the pipeline. The EFA-VI concept is picking up in India and more children with visual impairment are entering into schools.

Life is either a daring adventure or nothing. Security does not exist in nature, nor do the children of men as a whole experience it. Avoiding danger is no safer in the long run than exposure.

- Helen Keller

UPDATE FROM THE WORLD BLIND UNION

As discussed in our last article in *The Educator*, the World Blind Union will be holding its seventh General Assembly and fourth Women's Forum in Geneva Switzerland from August 15 – 23rd. We expect to welcome well over 500 delegates, observers and guests to Geneva.

In addition to dealing with the business of electing the Officers, receiving reports from the work of the Union over the past four years, approving constitutional amendments and passing resolutions that provide direction to the positions taken by the WBU and its priorities for action, the General Assembly and Women's forum will also provide significant opportunities for sharing expertise and information and for discussing issues of importance to blind and partially sighted persons.

Since the Assembly is being held in Geneva, the European seat of the United Nations and the permanent home of many of the UN Agencies with whom we work, we are taking advantage of that proximity to feature our work with the UN and its agencies in our program.

An exciting new feature for this Assembly is the inclusion of best practice presentations from our members in all Regions. One of these presentations will feature the EFA-VI campaign in Vietnam.

For further information about the WBU General Assembly, please visit the GA website at www.wbu2008.ch

The WBU, through the sponsorship of ONCE and in partnership with ICEVI organised a

Congress for blind and partially sighted children at the ONCE Educational Resource Centre in Pontevedra, Spain, from June 16 -20th. The congress, called "Listening to the Children" brought together 24 blind and partially sighted children from all regions of the world.

Participants had the opportunity to participate in debates and discussions on the status of blind and partially sighted teenagers in the world today, focusing especially on education, the family and relating to peers.

There were intercultural workshops and possibilities to participate in recreational and sports activities as well as excursions in and around the beautiful Galician city of Pontevedra.

One of our Strategic priorities for this current quadrennium has focused on improving access to books and other written materials. Our Copyright and Right to Read Working Group has been working tirelessly with IFLA and the DAISY Consortium to raise awareness about the lack of accessible printed materials and books and to promote the development of copyright legislation that would enable the sharing of books across geographic boundaries.

On April 23rd, the WBU launched a Right to Read campaign in Amsterdam to commemorate World Book Day. For further information about this important event, or to read the report of the launch and the speech delivered by WBU President William Rowland, please visit the WBU website at www.worldblindunion.org.

In addition to the work on copyright and the promotion of the production of books in accessible formats, the WBU has also been advocating with the Universal Postal Union to protect the right of free post for alternate format books and to promote expansion of the free postal provision to other aids and devices used by blind and partially sighted persons. This effort also involves informing and encouraging local governments to support the issue of free postage for materials for the blind.


As reported in our last article, the WBU has been extremely active in the development and

promotion of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We are delighted to report that as of 3 April, twenty countries ratified the Convention and it came into force as a binding United Nations Convention or Treaty on May 3rd. The WBU United Nations Working Group is presently developing a tool kit for use by our members at the national level, which clearly outlines the applicability of the UN Convention as it relates to improving access and rights for persons who are blind or partially sighted. Once complete, this resource will be made available on the WBU website.

For additional information regarding any of these items, please contact Penny Hartin, WBU Chief Executive Officer, at penny.hartin@wbuoffice.org or visit the WBU website at www.worldblindunion.org.

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Children and young adults with visual disabilities: ONCE work models to ensure an independent life

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“Independent life” refers to the power to have control over our own lives and the ability to solve problems / make good decisions on a daily basis. Apart from the type and degree of the condition, individuals with disabilities hold, and therefore must have, the same rights and opportunities to enjoy an independent life. One avenue to attain this goal, without a doubt, is to ensure individual self-reliance.

As a visual disability takes over, the ability of adult individuals to deal independently with daily living tasks is much reduced. For children who have enjoyed neither a visual experience nor preliminary training on said tasks, repercussions can be even more severe and their independence can be severely jeopardized in the future unless appropriate intervention is provided.

Most skills required to attain independence in life are acquired through visual imitation of peers and, thanks to this, many concepts are developed quasi spontaneously. In this sense, children with visual disabilities are indeed at a clear disadvantage. In addition, the skill acquisition process is steady between the first year and the age of twelve, a period in which children gradually and progressively take on an increasing number of activities as they build up their independence.

The influence exerted by both family and school on the development of the child is a key factor. However, it is necessary to ponder whether these two spheres are enough for the purpose of ensuring the level of safety and efficiency required for daily travel and activities. There is no doubt that many children will require specific attention, which must be provided by specialized services always within the framework of educational structures.

Therefore, systematic intervention is necessary in order to alleviate any difficulties that may arise.

The goal of this intervention is to ensure that the resources and strategies required for child independence are developed. One of the most significant services provided by ONCE¹ is the Rehabilitation Service (RS), as the areas it works on (orientation and mobility, daily living skills and access to information) are essential for individual independence. RS provides services to individuals of all ages, including children, young adults, adults and senior citizens, all with distinct needs and issues. In order to be functional, the child rehabilitation process takes into account their evolutionary development in specific, practical learning situations.

ONCE² also provides education services focused on supporting community education systems. The care service model that we are going to assess in this article is configured on the basis of said educational structures. Rehabilitation programmes are designed to cater to the specific needs of all children while focusing on their characteristics as part of an educational method geared to attaining the ultimate goal of independence.

The Spanish Framework of Education

The education regulations currently in force in Spain focus on the importance of schools to ensure that all children attain the required level of independence. Specifically for early childhood education (age 0-6), children of both sexes must “gradually attain independence in the development of their habitual activities”. Likewise for primary education (age 6-12), which is divided into three two-year stages, the priority is for students to “acquire the necessary skills required

for peaceful conflict resolution and prevention to enable them to interact independently with their families at home as well as with the social groups they are in contact with”.

Thus, within this framework, and taking into account that students with disabilities are, first and foremost, full citizens and that as such they must benefit from public education services, one of the school’s goals must be to help them achieve independence whether they require specialized support or otherwise.

The school must focus their activities on ensuring that children develop to their full capacity and acquire all the skills, strategies and habits that are necessary for individual independence.

Intervention Model

The ONCE Model of Social Services Provision is a key reference for the purpose of ensuring the welfare of the blind and the visually disabled.

The Case Manager³ (CM) position for children is held by the support teacher / tutor who, along with the Rehabilitation Officer⁴ (RO), is in charge of organizing the actions to be developed over time, and taking into account the following:

- The child’s competency level.
- Issues that may have an impact on learning: motivation, skills, expectations, family support, type of school, etc.
- Skills that must be acquired by children according to their level of development and needs.

¹ ONCE (*Organización Nacional de Ciegos Españoles* - Spanish Organization for the Blind)

² The ONCE Education Services provides services to 7,431 students, of whom 3,634 are in early childhood, primary and secondary education schools.

³ The CM coordinates service provision tasks to ensure they are adapted to the needs of each user.

⁴ The ONCE Rehabilitation Service team includes the RO, the Ophthalmologist and the Optician. The RO teaches the techniques required for individual independence.

These factors will determine the need of either direct specialist support provided by the rehabilitation expert or other indirect support services.

Spheres of Intervention

Intervention focuses on the following spheres:

a) *Family*

A key factor provides that relatives believe in the child's possibilities and provide him / her with an active role within the core of the family.

In order to foster these attitudes, families must be provided with all the required information to ensure that they help the child to reach his/her full capacity while learning not to engage in over-protective behaviour that only fuels increased dependence. When dealing with visual disability, it is hard for parents to stop taking responsibility for the child's basic needs (including personal hygiene, feeding, clothing, etc.) as they have done since the time of birth.

Therefore, it is essential that specialists focus their actions on the family environment. These actions can vary to adapt to current immediate needs: interviews, observation of work sessions, family meetings, talks, etc. The goals must be, on the one hand, to gather information on the level of performance reached in all activities and, on the other, to have them share the successes achieved over time - all of which ensure an appropriate level of involvement leading to securing steady support as well as sound integration of skills to pave the way to the child's independence.

b) *Support and Advice to Schools*

Despite the fact that integration and inclusion are provided for in the legal education framework, and that professionals are

increasingly sensitive and better trained, the presence of a blind or visually disabled child in the classroom always causes a certain degree of apprehension and insecurity.

Inclusion, the philosophical framework currently applied to education activities, implies focusing support not solely on the student but also on the school and the social environment.

c) *Environment adaptation*

Sound planning of the appropriate environment, which involves the prevention of hazardous elements, help lessen fear and anxiety in the child and prevents limitations to the child's initiatives following past unpleasant experiences.

It is thus essential to implement measures for the purposes of improving accessibility, removing obstacles, using tactile and visual signals, improving lighting conditions, etc.

Methodology

The Rehabilitation Service's performance focuses on the following programmes:

• *Assessment*

Defining the child's level of competency and determining the level of support required as early as possible. In addition, it also stresses ensuring continuous assessment of skills. The results will be used for the purpose of determining the following:

- Appropriate acquisition of skills.
- Any issues that call for more specific focus and attention.
- The goals that need to be worked on.

• *Direct / indirect intervention*

A programme will be prepared on the basis of the assessment results for the purpose of

determining the most suitable type of intervention (direct or indirect) and the level of involvement of each professional.

Contents

Contents involve the following aspects:

- Sensory and psychomotor development
- Concept acquisition
- Specific techniques and application
- Consolidation of attitudes

These aspects must be sequenced in accordance with the level of development specified on the curricula corresponding to each education stage.

Considerations corresponding to each education stage

Parents, duly supported by professionals, must ensure that their children have access to sufficient learning and development opportunities during their first years. Over time, children will become increasingly responsible and must have their say in education-related decisions and voice their needs and issues.

Intervention with children aged 0-3

During this time, the Rehabilitation Officer intervenes indirectly. However, it is crucial to specify the needs and to collaborate in the preparation of sensory stimulation programmes (visual, hearing, tactile, etc.), which will be applied at school and further developed by the supporting teacher. A system must be devised for the purpose of detecting behaviours or signs of development deviations in order to tackle the issues as soon as possible.

The visual stimulation programme acquires great relevance when dealing with children with residual vision. All related activities will be integrated and focused on the ultimate goal of achieving independence.

Providing advice and assistance to families is essential for the purpose of fostering and enabling successful skill learning practices.

Intervention with children aged 3-6

This is a key stage in which the child learns to relate to the environment and surrounding objects by means of direct experimentation. In the classroom, independence-building tasks are taught and the child, in order to feel equal to fellow students, needs to learn and complete them at the same time.

The preliminary requirements the child will need for orientation and mobility, as well as to acquire daily life skills, must be outlined during this stage. Many of these requirements are included in the school curricula. However, other more specific requirements cannot be forgotten - they must be integrated into the child's school and family life.

The RO applies a more direct method of work where required, specifically at the time of providing advice to the professionals working with the child on daily living related areas (teacher, lunchroom educators, etc.).

Intervention with children aged 6-12

During this stage, even though the teacher (Case Manager) is still in charge of the programme coordination, the RO is now more directly involved. As preliminary requirements are further developed, it is the time to focus on teaching specific techniques and tasks. On completion of this stage, the child will start to apply the strategies learnt and to carry out some activities independently.

All data gathered from direct work carried out by the teacher and the rehabilitation officer must be shared in order to enable comprehensive understanding leading to realistic and practical results.

The skills required for carrying out daily living activities - already introduced at school as specified in the curriculum - become increasingly complex. As a result, the RO will begin to work on said skills at the child's home.

Therefore, continuous collaboration with the family is required in order to further focus on and steadily work toward the set goals. This is the only way to ensure that the child correctly carries out at home the tasks learnt on a daily basis.

As for orientation and mobility programmes, it is never easy to set chronological age-based goals, for there are many factors involved. Firstly, it is the family that "allows" a degree of independence during travel and outdoors. The extent of *allowed* independence will depend on their attitude, type of environment and complexity. Other key factors to take into account include the student's skills (orientation and mobility skills, etc.) and attitudes (fear, carefulness, responsiveness, etc.).

Intervention with children aged 12-16

This is the stage in which all skills and concepts worked on in previous stages are further developed and applied to practical situations.

The application of skills by youth with visual disability is of paramount importance, as this stage coincides with life stages that involve profound changes affecting social relationships, activities shared with peers, increased independence from family, etc. In short, children are getting closer to the adult life stage, a stage in which they will need the highest degree of independence.

To conclude, we would like to mention Mr J. Vidal Garcia Alonso who, in the book *El movimiento de Vida Independiente. Experiencias Internacionales*

(Movement in Independent Life: International Experiences), of which he is the coordinator, states the following:

"The Independent Life proposal implies, in its practical development, setting an array of services to enable users to play life roles: student, worker, businessperson, mother / father, citizen, etc. Thus, an individual with a severe disability can live at a similar pace to any other person by focusing their energy on those tasks in which they can be more efficient".



When Ali goes blind: About disability and the meeting of cultures

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“Do you feel it’s a good thing to be independent of your family?” The Arabic interpreter waits for my reply. Meanwhile, Ali, who is blind, is puzzled by my hesitation. For my part, I am puzzled by his straightforward question. “Why, sure,” I say, hesitantly. The interpreter waits for me to elaborate, and when I do not, he translates my “Why, sure”. I am aware of the gap that has arisen between Ali and myself. I want to be able to reach out. How do I bridge the gap?

This is an authentic example from one of the first introduction meetings at the Institute for the Blind and Partially Sighted, where 12 years ago we established a rehabilitation service for visually impaired immigrants and refugees. They were to acquire adaptive skills and receive lessons about Danish language and culture. In the dialogue quoted above, the conversation that was supposed to mark the opening to a new life has already failed to meet Ali’s expectations.

When Ali was released from the prison where he had experienced torture, like so many of his countrymen he had to leave his country in order to save his life. While he was on the run with his family, a bomb explosion cost him his eyesight. Now, Ali is in Denmark – a blind man in a foreign country, whose language and culture are alien to him. In Ali’s previous life as a farmer, he had no need for book learning. Later, when he was forced into exile in the mountains and lived as a partisan, academic skills were of no use to him. Despite his almost inconceivable losses – of sight, native country, culture, and language – Ali still harbours a hope: the hope that this new, technologically advanced country will be able to cure his blindness.

Instead of a miraculous operation to offer him a life *without* his impairment, we now offer him a life where he might learn to live *with* his impairment! We explain that with the proper skills and assistive aids, he will be able to lead an independent life, and with the white cane he will

be able to travel independently without needing help from anyone. “So, do you feel it’s a good thing to be independent of your family?”

In the culture where Ali grew up, everybody relies on each other – for better and for worse, as an unquestioned fact of life. We have not considered this when we proudly present our comprehensive rehabilitation plan to Ali. It is based on Western ideas of self-reliance, independence, self-determination, and individual freedom. We talk about personal development and educational approaches. To Ali, our words express abandonment, coldness and the rejection of his needs. But, since he really has no other options, he enrolls at the Institute.

Our encounter with Ali and other visually impaired individuals from Muslim cultures was an encounter with a different perception of impairment and disability. It sparked many reflections and adjustments, as the questions these students asked seemed to cast doubt about the very basis of our services and, in fact, key values of Western culture.

Our students acquired the skills we taught, but they did not use them in practice. Every afternoon, Ali and his fellow students were picked up by relatives who virtually carried them home despite their mastery of white cane techniques. The passive resistance that we encountered in our courses and the mental resistance against transferring the acquired skills into daily practice were incomprehensible to us until we stopped viewing the students exclusively as individuals.

Ali comes from a society that is permeated, at every level, by Islam. The family is the core unit, and in every aspect of their existence, individuals rely on the community. The family network affects the individual’s life on every level: personally, socially and economically. No decisions are made without the inclusion of the family, and no problem is solely the burden of any individual. In exchange for personal freedom, the individual receives the

full support and attention of the family. Anthropologists call this collective family structure a sociocentric society. By contrast, the Western egocentric society is structured around the individual. Only by understanding and acknowledging the collective family structure can we ever reach out to the Muslim man or woman.

If a visual impairment is seen as Allah’s will it is inappropriate to display one’s impairment in public. On a religious and cultural level, using the white cane in public means challenging the fate handed out by Allah. On a social level, it is a slap in the face of the family whose honourable duty it is to assist the blind family member – for example, by acting as his guide for the rest of his life. On a personal level, Ali loses his anonymity twice over since he stands out both as a foreigner and by virtue of his white cane.

The visually impaired immigrant or refugee faces the requirements of a dual integration process: integration into the world of the sighted and integration into Danish society. Both require a basic trust in the world that one is seeking to gain access to, a tall order for a victim of torture who may have lost his basic trust in others. The entities we turn to for assistance: police, the courts, doctors - all failed Ali when he was arrested by the police, the courts turned a blind eye, and doctors monitored and sanctioned his torture.

We offer our students 25 lessons taught by highly qualified professionals on a one-to-one basis, involving carefully planned experiences and activities, but we do not offer them what they expect: caring, friendship and understanding. In the collective society, a person is not victimised because he loudly expresses his pain. It is any family member’s right and obligation to make his predicament known, so that others can step in and offer their assistance.

A good place to begin when dealing with a Muslim person in need is to acknowledge that he or she is embedded in a family context; telling them that

you sympathise with their situation and that you understand how difficult it is for them to carry out the duties expected of them is a good start. That provides a shared basis for dialogue. Doctors, teachers, social workers and other professionals who have taken over the tasks that were traditionally the domain of the Arabic family are not trained to share private thoughts or offer sympathy. For fear of seeming unprofessional, many come across as impersonal and cold. When I initiate a conversation with an Arabic woman, I always throw my personal life into the balance by telling her something about my own family.

When a patient or a student brings the entire family along when they come in for appointments, the reason is that the issue at hand concerns the entire family and not just the individual. We should include the family instead of being put off when we see that a whole group of people has shown up.

The sociocentric society has a pluralistic view on disease and, consequently, on impairments. Thus, there are several simultaneous approaches to understanding disease and impairments, all equally valid: The biological view, the traditional view, and the religious view. Each of these domains is an independent entity with its own perceptions of the cause and proper treatment of disease. The various approaches or models do not mix! Because of this pluralistic perception of disease, the Muslim patient has different expectations of doctors than the average Danish patient – expectations that often lead to conflict. There seems to be a built-in paradox in the Muslim patient’s view of doctors. On the one hand, doctors enjoy great respect, and many patients seem to regard doctors as powerful and undisputed authority figures. On the other hand, the same patients seem to view their visit to the doctor as one of several elements in a treatment process. The model illustrated below describes the pluralism that typically characterises the explanation and treatment of disease and impairment in a sociocentric family pattern.

FAMILY	
Cause	: Lifestyle
Expert	: Mother in law
Treatment	: Care and advice
TRADITION	
Cause	: Spirit/Others
Expert	: “Wise woman”
Treatment	: Talisman
RELIGION	
Cause	: Allah’s will
Expert	: Imam
Treatment	: Prayer
BIOLOGY	
Cause	: Physical malfunctions
Expert	: Doctor
Treatment	: Pills and injections

In the patriarchal family, the husband’s mother, the mother-in-law, is the expert on health issues. She issues the guidelines for healthy living that explain disease or impairments. An eye infection, for example, is to be treated with herbs.

In the religious model, all events are interpreted as reflections of Allah’s will. Thus, bearing a blind child may be viewed as a punishment or trial that the family must endure and often tries to hide. The imam is the expert who is consulted for guidance on the proper prayers and behaviour according to religious scripture.

The traditional model springs from pre-Islamic tradition and is rejected by Islam. Tradition is still strong in many villages. This model points to evil spirits or the envy of others as the cause of disease or impairment – the evil eye, which may be warded off by a talisman prepared by the wise woman in the village.

The biological model is the doctor’s domain – provided he sticks to the physical and tangible sides

of the profession. The traditional Muslim patient expects the doctor to locate malfunctions and fix the body, preferably with pills and injections. Psychosomatic and social contexts are the domain of the family, spiritual aspects the concern of religion, and any metaphysical explanations belong to the world of tradition.

Importantly, these explanations, pieces of advice and treatments are always discussed in the family, which has the final say in the matter. Once the family has decided that a disease is the result of immoral living, it is difficult for the doctor to suggest anything else. Hence, although doctors appear to be treated as authority figures, their diagnoses may still be rejected. If, furthermore, their approach is very Western, the chance of compliance will be further reduced. For example, if he appeals to the patient, as we do in our democratically minded country: “Don’t you think it might be a good idea to wait a few days to see if the fever goes away?” This approach might make

a Muslim patient feel that he is faced with an insecure doctor whose advice is not worth heeding.

And, of course: They show up late and forget to cancel appointments. What might seem disrespectful is in fact a lack of understanding that our Western society relies on punctuality. Time is important – time is money. Other cultures do not place the same importance on time and punctuality. People do not make appointments with the doctor. They show up in the clinic in the morning, take a number and wait – for hours – to see the doctor without getting impatient or upset. When a Muslim patient is told that he needs to make an appointment, he might say, “But how does the doctor know how much time the patients need?”

The diagram below outlines “our” services versus “their” expectations in the encounter between “us” as professionals and “them” as clients or patients from traditional Muslim communities.

We offer	They Expect
<ul style="list-style-type: none">• Help to live with one’s impairment• Rehabilitation• Training• Social services• Technical solutions• Professional assistance• Self-reliance• Independence• Biological explanations• Diagnoses• Equality• Dialogue characterised by equality• Objective symptom descriptions• Conversation with individual client	<ul style="list-style-type: none">• Help to live without an impairment• Surgery• No personal development• Compassion and care• Medical solutions• The family’s assistance• Life-long support• No explanations• No interference in the search for a cause• Hiding one’s impairment• Authoritative expert advice• A free display of emotions• The presence of the entire family

We should not turn our values and social structures upside down, but we should also avoid clinging to values that do not stand up to close scrutiny. We need to have sufficient insight into

the values and norms of other cultures that we can move beyond them and meet each other where cultures lose their distinction, and we are left with universal human qualities.

Independent Living

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This article will give a glimpse into the American perspective on independent living for blind and low vision individuals. It is a life encompassing and complex issue. The factors that constitute and impact independence will be addressed.

Independent living means different things depending upon age, cultural background, and the presence of additional disabilities. Considering the broad spectrum of the population of visually impaired individuals, the following factors are the underpinnings of independent life for everyone. Individuals must have and know their purpose in living. Each person must feel able to contribute to society. Independence is having a meaningful life, a life of quality. A person needs to understand his or her own strengths and areas of need. Throughout life and in every step toward independence a person needs to feel good about him or herself.

Independence is often mistakenly considered to be the ability to do things without help. America is the country of the rugged individualist; to many, if you need help it connotes weakness and lesser ability. Yet, being visually impaired is synonymous for needing help with certain things. I believe that being independent means knowing yourself well and knowing how to meet your own needs, with or without the help of others.

What does it mean to live independently? It means to feel that you have autonomy, that you are in charge of your life and responsible for it. It means that you have the opportunity to take care of yourself to the best of your ability. It means you can access the information you need. You can go to the places you want to go. All people, with or without vision impairment, have to strike a balance between feeling independent and being comfortable asking others for help. In many ways, all people want to feel loved and cared for, to have someone concerned about their welfare,

to share ideas and to share responsibility. That is what happens in families. Everyone wants the opportunity to choose however, when and how they are interdependent, and those with visual impairment are no exception.

Legal Foundation

Independent living in the United States is as complex and varied as the 10 million adults and children with visual impairments who live here are. This is a very large country with a wide array of services, not under any national umbrella for the visually impaired. Across the country, every individual with a disability is protected and guaranteed civil rights and equal opportunity through important legislation signed into law over the past 35 years.

The first of these is Section 504 of the Rehabilitation Act of 1973, which prohibited discrimination toward persons with disabilities in federally funded programs.

In 1975, a landmark education law was enacted, PL 94-142, “The Education for All Handicapped Children Act”. This mandated that children age 3 to 21 years old receive a free and appropriate education in the least restrictive environment. In 1997, this law became the “Individuals with Disabilities Education Act” (IDEA) and mandated programs 0 to 3 years. These laws are the foundation of the entire special education system in the United States.

The Americans with Disabilities Act (ADA) of 1990 was designed to eliminate all remaining barriers that could prevent people with disabilities from participating fully in their communities. The provisions of the law aimed at eliminating discrimination in employment, public accommodations, telecommunications, and public transportation. The ADA has brought

persons with disabilities into public awareness, but there is still much to accomplish. This is one

reason why encouraging independence and individual responsibility is crucially important. Although excellent laws are in place, the onus of making the ADA work falls to the individual with the disability. That person is not always sufficiently trained or knowledgeable to advocate and fight for the necessary change. In many instances, the status quo system does not want or welcome challenge.

Key Factors for Independence

Literacy

Literacy is a key component in independent living. Reading and writing are fundamental to success. Braille is having a much-needed resurgence in special education for the visually impaired. For many individuals with low vision, glasses and optical aids are essential for the ability to read. Although vision may be a sensory disability, many individuals, both blind and with low vision, read for pleasure as well as for work. With the use of magnifiers and monoculars, small print and print at a distance can be accessed. Screen readers, braille displays, and screen enlargement software have made reading from the computer possible. Recorded books, MP3 format books, and Audible materials have greatly increased the ease of reading.

Mobility

The ability to move around comfortably in the community in which you live and work is vital to independence. The United States has a vast variety of options of where to live. Large cities often have the transportation and services which make independence easier. Small towns offer the advantage of walking to places such as schools and services. People choose what means of mobility they are comfortable with using.

Almost all children, blind and with low vision, receive extensive orientation and mobility training. This constitutes use of the white cane,

learning how to take public transportation, using monocular telescopes to locate street signs, and learning how to access the paratransit system. Paratransit is an alternative mode of flexible passenger transportation that does not follow fixed routes or schedules. It is door-to-door service for a small fee. It became available for people with disabilities through the ADA. There is an expectation that visually impaired people can travel alone in familiar routes. Children with additional disabilities are taught to take paratransit or to travel with a companion.

There are reduced fares on public transportation in most cities and on the national rail system, Amtrak. US airports, like those in many parts of the world, have assistance for disabled passengers. Airlines seem to understand the concept of low vision now and often assistance is respectful and helpful. There is still much yet to do in this area as a person still needs to be savvy to navigate the system. Also, limited transportation in some areas and the inability to get to a job are strong considerations in the high unemployment rate of blind and severely visually impaired adults in the United States.

Access to Goods and Services

The ability to buy groceries is essential to independence. At an early age students are taught to shop, to ask for Customer Service in the grocery store, and to handle money. Access to food is often easier in a large metropolitan area where food can be ordered online and delivered to your home. Large department stores will often have personal shoppers to assist in finding clothes. The internet has revolutionized shopping. If a visually impaired person has access to the internet, shopping can be accomplished without the need for transportation. These services require a certain amount of skill and people need to be made aware of them and taught how to use them.

Meaningful Work

Everyone needs to have work that is personally satisfying and that provides income with which to live. To that end, the United States has an extensive program of transition to begin the preparation for the world of work for students from the age of sixteen. From IDEA, “transition is designed to be a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation”. It is based upon the individual child’s needs, strengths and interests.

Transition services are in partnership with the Department of Rehabilitation. Rehabilitation is a federal program, but it is administered in somewhat different ways by the individual states. In all states there are services for blind individuals; however, they vary in delivery model. For example, the following is the mission statement of the California Department of Rehabilitation: “The California Department of Rehabilitation works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living and equality for individuals with disabilities.” Every effort is made to identify and enhance the interests and skills of each individual in order to gain meaningful employment.

Social Relationships and Support

The development of good social skills is crucial to independence. Students need direct instruction in learning the social cues and mores that sighted children often pick up incidentally. Communication skills, self-advocacy skills, socially acceptable behavior and attitudes all underlie success.

National organizations of the blind, notably the National Federation of the Blind (NFB) and the American Council of the Blind (ACB) offer support through state chapters, meetings, conventions, trainings, and social events. These organizations can give vital encouragement and foster friendship for many people.

Personal Perspective

I am a special education teacher and a licensed therapist and have lived with low vision all of my life. I have been active in the field of special education for the visually impaired for 35 years. I live and work in an area where transportation is excellent and I can safely walk to many places in my community. I have raised three sons and have felt capable and confident. I am very aware of the everyday challenge of maintaining a sense of independence. The greatest is not driving. In Northern California, we have a fast paced, far-flung metropolitan area. We have excellent public transportation and yet, there are many beautiful places that are very difficult to reach without driving.

Allowing the needed time to accomplish tasks is another source of potential frustration. Public transportation, walking, biking, all take longer than driving. Searching for things in stores and shopping takes longer. These are small inconveniences, though, and inconsequential to living a rich, full, independent life. The support of family, friends, and others with visual impairment has been essential to my independence. When I was in school there was an inherent expectation that I would do well and keep up with my classmates. I internalized these high expectations as a young person, and I believe in them still.

Important Factors to Consider

Several factors need to be kept in mind when looking at all aspects of independent living. Age of onset of blindness is very important. A newly blinded adult or child will experience a great

change in their life and often profound grief at the loss of the ability to see. Whether a person has a stable or progressive vision loss will impact what adaptations to use and what type of help to engage. For people of all ages, it is important to understand how the family has accepted the visual impairment. Unresolved familial issues of grief, sadness and or anger can greatly impede the successful independence of the visually impaired person. Socioeconomic background and education play a role in access to resources and personal advocacy. The United States is rich in cultural diversity. Many cultures differ in their approach and attitude toward blindness. Shame and fear are not uncommon emotions. Society in general does not understand the capabilities of those who are blind or have low vision.

There are factors that can enhance success for independent living. The use of mentors, who are themselves visually impaired, is a powerful intervention. It is vital to feel that you are not alone in your experience. Support groups can offer ideas, suggestions, experience, and much needed camaraderie. Camps and summer programs can offer the same to children. Collaboration between programs, such as education and rehabilitation for young adults, and senior centers and rehabilitation for newly blinded elderly, can assist in navigating the complex array of services.

In Conclusion

The United States values independence for blind individuals in whatever form is meaningful and possible. This value is fundamental to all of education, transition services, and rehabilitation. The skills necessary for independence are taught throughout school and training into adult life. Financial support is available through the Social Security system if supplemental income is necessary. We believe in each person's inherent right to "life, liberty, and the pursuit of happiness" (United States Constitution) and aim our efforts to that end.

Spatial Intelligence: The art of adapting the surroundings and their permanent changes to be able to move around safely and successfully

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Specialized literature about sensory and perceptive skills has paid little attention to consciousness and spatial orientation. Specifically, little attention has been given to concepts like position, distance, direction, location and others related to the skills necessary to face constant changes and be able to adapt the spatial surrounding to what best fits us.

By **Spatial Intelligence** I mean the effective use of the above mentioned sensory and perceptive skills. This intelligence will make it possible for visually impaired individuals to be as safe and independent as possible while moving outdoors, indoors and in both known and unknown areas. Sensory and perceptive skills start to develop when the blind or visually impaired baby is born, and continue throughout life since the overall tactile, visual and perceptive scene is in constant change.

In order to foster the development of spatial intelligence at an early age, it is necessary to have methodological and educational elements that will allow us to achieve a transdiscursive commitment of all actors and resources, especially parents, teachers and instructors, in the family, school and community settings. In this way, the blind and visually impaired will have access to a better life, moving around happy and fearless, feeling confident and self-sufficient.

The art of adapting to the surroundings and their permanent changes

In this ever-changing physical and visual surrounding, it is crucial to be able to adapt by interpreting the spatial codes around us, so as to be oriented and move around safely.

Visually impaired individuals resort to their sensory-perceptive potential and decode, interpret and use the messages provided by space in order to solve these two questions: what are my surroundings like? And, what is my position in these surroundings?

We should learn to process the perceptive information around us at an early age, starting with the simplest perceptions we get in private spaces, like the cradle, the bedroom, our house, the classroom. Then, it will be possible to move forward to more distant and complex spaces; but this will depend on the interests and needs of the blind or visually impaired individual.

To be able to functionally use our spatial intelligence, it is necessary to identify and distinguish the spatial messages by analyzing the environment where the practices and activities of the teaching/learning process will take place. Such analysis will be carried out by the Mobility instructor together with the blind child or adult.

For the sake of this presentation, **spatial code** refers to any message that comes from the space, is perceived through our sensory-perceptive resources and then becomes a useful element:

- To estimate the distance between objects, between objects and myself; and to perceive their location and direction when moving.
- To establish a relationship among objects and therefore, determine which are the safe areas to use when moving between places.
- To know my position in space and be able to move safely.

By making a functional use of the spatial codes, we will develop our spatial intelligence. But before that can be done, it is necessary to understand and identify our surroundings and their changing elements – like lighting and weather conditions – since these may modify the value of the spatial code.

The space has infinite characteristics that will be identified depending on the perceptive needs and the kind of activity to be pursued. Among these characteristics we can find the dimensions and features of objects; the relationship between

objects, and between objects and individuals; the distance, location and permanence of objects; and amplitude, in all directions.

Visually impaired individuals, regardless of their visual capacities, need to have a fully developed perception to successfully identify the various environmental, physical and visual codes. It will then be necessary to interpret and use those codes effectively in everyday life before we are able to transfer the spatial data from a familiar surrounding to one that is partially or absolutely unfamiliar.

The apparent dimensions of an object change according to distance. That is why every subject calculates distance differently. Something similar happens with the permanence of the shape of the object; therefore, we should help our students and children to estimate the distances, shapes and relationships among objects.

Lighting conditions, like luminance, dazzles and spatial depth can distort the estimated distance and the relative position of objects perceived by people with low vision. The quantity, quality and origin of light, whether natural or artificial, are the factors that most modify the perception of the visual-spatial code.

In rural areas – where perceptions need to be estimated differently – temperature, rain, humidity and dust, among others, also interfere in the visual appreciation of what surrounds objects and people. This could lead to distorted appreciations of distances, dimensions, shapes and other elements of space and objects.

In the city, the colour of buildings, the brightness of light, the effects of luminance, the shades and contrasts, and the surrounding obstacles around should be considered before planning, suggesting, teaching and even assessing the development of Spatial Intelligence.

Similarly, the panorama in rural areas can be influenced by weather factors, like rain, dust, fog, the effects of evaporation, the sun and the colours of vegetation and the land. We can then conclude that spatial codes or messages will vary constantly according to the weather and geographical conditions of the surroundings.

Tips for the development of spatial intelligence at home or school

In the classroom or the bedroom, decide which would be the best place to put auditory or tactile guides. For instance, place a rattle in the entrance, probably at the door, so that every time the door closes or opens, the auditory guide would indicate the distance and position of each student in relation to the door. In this same way, we can put several guides (both auditory and tactile) in different spatial areas, like toilets or corners.

Guides could also be used to determine distance and location relations between the classroom or bedroom and other parts of the school or house.

It is also advisable to organize personalized sessions with students, both at home and in the community, to explore the different spatial areas that surround them.

As educators of space and mobility, we should:

- Help the students to understand what they see, hear or feel to be able to estimate distances and the location of objects and people.
- Help them identify personal and environmental factors that may alter the visual or tactile surroundings.
- Assess, together with the students, the characteristics of the spatial codes of immediate and distant spaces.
- Show the students possible aids of spatial interaction to see better, feel better, take

advantage of the different elements around them, and know about the optical and non-optical aids that would be useful for an effective interaction with the surroundings.

- Teach them how to dodge obstacles, by explaining when to use the opposite sidewalk, how to avoid shade, offset a glare, change the route when necessary, train visual memory to be able to make unexpected decisions when the visual perception is not certain, etc.

The abovementioned tips and activities are just a small methodological guide for the purpose of helping our visually impaired students and children develop their spatial intelligence effectively and functionally. I am convinced that the creative spirit of parents, teachers and instructors in Mobility will nurture the didactics and methodology for a better development of spatial intelligence.



Independence, Education and Technology: An inevitable formula of the future

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These days, technology can be found everywhere: it is in our homes, in post offices, in schools and everywhere else in our everyday lives. Indeed, technology has changed the way we live, work, interact with others and even think about the world around us.

Many people in different countries have embraced technology in one way or another, i.e. they own a mobile phone, use the Internet, watch television etc, because it brings a new level of comfort and a great number of opportunities not available to previous generations.

How can this technology be best used to improve lives of visually impaired children? Are we utilizing technology to its full potential and, if not, what can parents and educators do to change that?

In searching for examples of how technology affected my personal life, two of them immediately come to mind. During my Philosophy studies at the L'vov University in Ukraine I had to take a course in computer science.

Knowing nothing about computers, or having no idea of how I would use one, I approached my professor for this class to find out about my participation and, more importantly, how he would grade me. After several minutes of thinking my professor got back to me and said that the only thing he could think of was to show me how to play music on the computer. Otherwise I was free to skip classes and answer some theoretical questions during the final exam. For the next four months I enviously listened to my classmates telling me about challenging programming projects they were working on in the class while I spent most of my time learning “dry theory” that carried no practical application for me.

Several years later during one of my Computer Science courses at Temple University in the US,

when a rather similar situation presented itself, my professor asked me to advise him on the approach that would help me stay engaged in the class. After consulting with each other for several minutes, we decided that I would team up with one of my sighted peers who would read the computer screen to me, and I would jot down my answers into my electronic note taker.

This time I was not given a “free ride”, but my teammate and I were required to come up with our own answers for given problems.

As I further leaf through my memories of the past, another image presents itself before my mind, an image of me standing at some unfamiliar train station in a small Polish town.

I recall that I had ended up there erroneously by purchasing a ticket for the wrong train.

No cell phone, no GPS to help me out, my only two “secretaries” were my white cane and the common-sense “ask people” strategy. Suffice it to say that I eventually reached my destination in the end having spent twenty-six hours instead of my originally intended twelve hours of traveling. Several years later, cell phones became omnipresent, and in the beginning of 2000s, the first talking navigation system for the blind was introduced.

I brought up these perhaps somewhat extreme examples to emphasize the two major aspects that help a blind person better integrate into mainstream society: education and independence.

The two are intertwined in that each one helps to advance the other. For example, being able to attend a school or a university requires an ability to travel independently. On the other hand, with a degree in hand one is able to invest in his or her independence by getting employed or starting a business of one’s own.

Furthermore, knowing about and using technology on an everyday basis helps young children and teenagers with visual impairments establish and maintain social relationships with their sighted friends, for whom cell phones and I-pods have become not “I want it” but “I have it” reality.

Capitalizing on the advancements in technology, and assistive technology in particular, is not only our right but a responsibility. For a young generation, being independent includes befriending technology and using it to advance their knowledge of the world and of the mainstream culture, be it through the Internet, travel or their sighted peers.

These days technology, from easy-to-operate digital audio recorders to 100-dollar laptops, finds its place in the most remote or less wealthy parts of the world. However, it has taken many years before the results of technology’s involvement became apparent, particularly in cultures where technology has not traditionally been utilized for everyday or educational activities.

One of the most vivid examples of societal transformations through technology can be traced in South East Asia - in countries such as Vietnam, the Philippines, Thailand, Malaysia and others. Through the extensive help, or rather investment, of the ON-NET (Overbrook Nippon Network on Educational Technology) project and other organizations, the number of visually impaired computer users has grown from tens to thousands, many of whom received their university degrees and/or are employed by various local and international organizations.

What was most valuable about the ON-NET project, however, is that from the very start the realization was that the rate and the quality of technological advancements should be decided by local individuals and organizations whose

knowledge of their culture was better than that of the outsiders. Today, in all of the above-mentioned countries local blindness organizations conduct their own computer training courses, share their experiences with other regional organizations and advance awareness about technology in their own countries.

It is the keyword “investment” that I would like to linger on for a little longer. Just like ON-NET invested in the future of visually impaired throughout South East Asia, in a similar way our parents and teachers around the world invest in their children and students empowering them with the knowledge and skills that enable them to independently pursue their dreams.

However, in the world of today, in order to lead an independent life, one needs to have a good command of technology and, more importantly, understand how to put it to the best use necessary for achieving one’s goals. For example, during my Philosophy studies back in Ukraine, I had to rely on my classmates to read most of the literature for me because the required books were not available in Braille.

Today I can take the book, scan it, and convert it into text or audio. Then I can read it either with a speech synthesizer or listen to it on an MP3 player. Similarly, if I wanted to learn more about a particular subject discussed in class, I had to ask someone to go with me to the library and read for me or, what happened often, give up on it if the help was not available. All it would take to satisfy my curiosity today would be to go to the Internet and find my information through Wikipedia, a free encyclopedia, or through other electronic sources.

Could my Computer Science professor from L’viv University have done better than just letting me skip classes? Could he have followed a similar route to that of my professor from Temple University who let me suggest to him the best arrangement to keep me engaged in the class? Very likely, with a bit more persistence on his part we could have come up with some kind of engagement process where I could have participated in the class together with my classmates and had more pleasure earning my final grade. At the very minimum, my participation could have been an interesting experiment for him and the class.

Both professors probably had no experience in working with blind students or believed that it was possible for a blind individual to use a computer, however, each of them handled the situation differently. One relied on his own knowledge about blind people to come up with a solution to a problem, while another allowed the blind person to be his guide to help come up with necessary accommodations that worked for both the teacher and the student.

The trust in the abilities of students with visual impairments should be an essential part of teaching. The teachers do not always have to have the answers of how best to accommodate students, but they do have to believe that the students are capable of learning. This belief is what makes it possible to come up with creative solutions for introducing technology to students. It is clear that cell phones, the internet, MP3 players and talking navigators are here to stay, thus a more radical and more creative approach to educating visually impaired children needs to be adopted where technology is included in the curriculum as early as possible.

Self-pity is our worst enemy and if we yield to it, we can never do anything good in the world.

- Helen Keller

Special Interest Group – Education of persons with Batten Disease

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At the ICEVI European conference in Dublin, July 2009, one track will hopefully focus on a neglected or almost unknown area of special education, namely education for children and young adults with Batten disease.

There are two main reasons behind the neglect of this condition. Firstly, the target group has a very low incidence. For instance, there are approximately only 80 individuals with Batten disease in Sweden and Norway together. Secondly, the nature of the disease: these children and young adults have a significantly shortened estimated lifespan; they will, over time, require more and more assistance or support and more and more special education.

This challenge within education requires knowledge and an alternative educational platform. It must be remembered that a substantial part of these children's and youth's lives content is closely associated with their lives in educational and school environments.

The limited research into Batten disease covers the implications for the family of providing care for children and young adults particularly in relation to stress (Labbe 1996; 2003) and the wider implications of the experiences of families living with Batten disease on our understanding of disability within society (Scambler 2005). There is ongoing research looking at the support needs of families with Batten disease funded by the Batten Disease Family Association (Scambler & Williams 2005). There are a number of studies looking at use of medications and therapies in the treatment of young adults with Batten disease, but these focus very much on medical treatments and symptom control rather than the psychosocial support of this group of young people with families. Many authors stress a need for a supplementary focus on rehabilitation for children and youth with Batten disease.

Public support is required if we are aiming at participation for the target group. Families of children and youth with Batten disease are part of one of the most vulnerable groups one may find in our society. The state and local areas and communities have, according to the UN Convention on the Rights of the child, special obligations.

Article 23, §3 says that the State should ensure *“assistance and financial resources..... to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities”*. Article 31, §2 says that the *“State parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity”*.

Not much has (so far) been recorded and documented regarding education for children and youth with Batten disease despite the very special needs of these children and young adults. The aim of organising special themes/streams, focusing on education for these children and youth within existing conferences such as ICEVI, is to highlight the special challenges teachers for these children meet in everyday classroom situations, to ensure that inclusion and participation requirements are met, and to ensure that these children's special educational needs are met.

Conferences such as ICEVI Europe 2009 in Dublin, where educational knowledge and experiences are shared among professionals and practitioners within education might be a starting point for development.

The First International Batten Education Conference in Örebro, Sweden, in 2006 was the

first important step to highlight education for children and young people with Batten disease. The ICEVI conference in Dublin 2009 will hopefully continue this development.

How well this can be achieved through expanding our knowledge and sharing experience is very much dependent upon your participation. We, therefore, kindly ask teachers and pedagogues with experience and knowledge within the field to address their knowledge and interest by submitting an abstract on an educational or related topic to the conference organisers on an aspect of Batten disease. Such dissemination of knowledge will help us to promote professional networking, education development and pedagogical research in the field of Batten disease and, most importantly help support the young people with Batten disease and their families.

Details regarding how and when to submit an abstract will be made available on the ICEVI-Europe web site www.icevi-europe.org. If you would like any advice or suggestions before submitting an abstract please do contact us via email to Peter Rodney, pr@ibos.dk, member of the scientific committee.



Consciousness of educated people on their attitude towards disability - A step towards independence

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Attitude and behaviour are determined by the conditioned part of the consciousness. How does human conditioning take place? Bentham, a British philosopher wrote about 250 years ago that man lives under an empire of pleasure and pain. This is because every experience is recorded in our memory which throws up negative or opposite feelings recorded on an earlier action. This experience is not only individual but collective.

Attitudes are regarded as latent or inferred psychosocial processes that lie dormant within a person unless evoked by specific referents (Antonak & Livneh, 2000). Because of differences in physical appearance or mental capacity, people with disabilities are often perceived as crippled, childish, useless, dangerous, and abnormal. They have problems in receiving equal access to education, employment, health care, and social activities in communities (Brostrand, 2006; Gordon, Feldman, Tantillo, & Perrone, 2004; Hernandez, Keys, & Balcazar, 2000; Tsang, Chan, & Chan, 2004; Yuker, 1988). Although attitudes towards people with disabilities are improving, the primary source of the difficulties encountered by people with them is still the public attitudes rather than a person's physical or mental limitations (Chubon, 1992; Hahn, 1993; Vash, 2001).

The author of the article carried out a study involving 272 persons to investigate the level of consciousness of them towards disability. The classification of the sample is given in Table 1:

Table – 1
Classification of Sample

Occupation	N
Academicians	123
Rehabilitation Professional	72
Administrator	77
Total	272

Siller (1976) pointed out that attitudes and reactions to the handicapped are wide ranging and complex. They are based on variables related to important attitudinal formation such as family background, culture and personality. Age, sex and other demographic variables appear to be significant determinants in the manner in which attitudes towards the disabled are expressed rather than in their formation. Based on this background, the investigator discussed with several eminent experts in the field about the nature of the tool for the study, known as Disability Consciousness Questionnaire (DCSQ). The questions of the tool consisted of questions having Yes/No, 3 point choices and open ended choices. These items were grouped into four sections, namely, A- Consciousness about Disabled Child, B- Consciousness about Parent Perception,

C- Consciousness about Caring in Action, and D- General. This DCSQ was then field tested through a pilot study. The results of the pilot study were analyzed and on the basis of the analysis, the items which were considered irrelevant in the views of the experts as well as the objectives of the study were dropped. The final tool consisted of 74 test items and the maximum score possible was 200.

Data Collection

The Disability Consciousness Questionnaire was mailed to about 500 persons belonging to the identified areas. The investigator received 272 completed questionnaires after two reminders. The number of category-wise respondents from whom the filled questionnaire was received is shown in the table 2 below:

Table - 2
List of Respondents in Various Categories

Variables	Categories	N
Gender	Male	164
	Female	108
Educational Status	Graduates	93
	Post Graduates	98
	M. Phil/PhDs	81
Occupation	Academicians	123
	Rehabilitation Professionals	72
	Administrator	77

Data Analysis:

The analysis pertains to four areas namely: A - Consciousness about Disabled Child, B - Consciousness about Parent Perception, C - Consciousness about Caring in Action, and D - General. The area concerning A, i.e., Consciousness about Disabled Child, has 15 items on a three point rating scale. Area B, i.e., Consciousness about Parent Perception, has 23 items on a three point rating scale. The Area C, i.e., Consciousness about Caring in Action, has

22 items on a three point rating scale. The area D, pertaining to General has 14 items on a three-point rating scale. However, some items pertain to only dichotomous types of responses with response options *yes* and *no*. The DCSQ was analyzed table-wise by applying appropriate statistical procedures. The analysis drawn from and calculated on the basis of various statistical measures is mentioned below in tabular form.

Table - 3
Descriptive Statistics on the basis of Gender

	GENDER	N	Mean	Std. Deviation	Std. Error Mean
Consciousness about Disabled Child	Male	164	177.91	31.11	2.43
	Female	108	173.55	36.23	3.49
Consciousness about parents' perception	Male	164	188.89	27.38	2.14
	Female	108	180.77	31.94	3.07
Consciousness about caring in action	Male	164	191.04	34.02	2.66
	Female	108	189.26	31.41	3.02

Table - 4
T- Test for Equality of means between Gender

	T	Df	Sig. (2-tailed)	Mean Difference
Consciousness about Disabled Child	1.059	270	.290	4.36
Consciousness about parents' perception	2.239	270	.026*	8.12
Consciousness about caring in action	.436	270	.663	1.78

* Significance at .05 level

* * Significance at .01 level

From the above tables it can be inferred that men are more conscious about parent perception as compared to their female counterparts.

EDUCATION

Table - 5
Descriptive Statistics on the basis of the variable - Educational Status

	GENDER	N	Mean	Std. Deviation	Std. Error
Consciousness about Disabled Child	Graduates	93	160.25	38.37	3.98
	Post Graduates	98	184.27	27.53	2.78
	M.Phil / PhDs	81	184.68	26.14	2.90
Consciousness about parents' perception	Total	272	176.18	33.24	2.02
	Graduates	93	168.23	39.66	4.11
	Post Graduates	98	195.14	16.35	1.65
	M.Phil / PhDs	81	194.22	16.59	1.84
Consciousness about caring in action	Total	272	185.67	29.49	1.79
	Graduates	93	175.70	46.71	4.84
	Post Graduates	98	198.81	17.42	1.76
	M.Phil / PhDs	81	196.89	20.56	2.28
	Total	272	190.33	32.96	2.00

Table - 6
One Way Analysis of Variance (ANOVA) for Educational Status

		Sum of Squares	Df	Mean Square	F	Sig.
Consciousness about Disabled Child	Between Groups	35865.461	2	17932.731	18.300	.001
	Within Groups	263604.068	269	979.941		
	Total	299469.529	271			
Consciousness about parents' perception	Between Groups	43018.297	2	21509.149	30.037	.001
	Within Groups	192628.258	269	716.090		
	Total	235646.555	271			
Consciousness about caring in action	Between Groups	30433.669	2	15216.834	15.509	.001
	Within Groups	263930.886	269	981.156		
	Total	294364.555	271			

It can be seen from table 6 that education has a significant impact on the consciousness about the disabled child, parent perception, and consciousness about caring action as the T value shown is statistically significant at .01 level of

confidence. Post graduate respondents have higher consciousness levels as compared to those of graduate respondents. The level of consciousness of this group of respondents towards disability is higher in all the scales.

OCCUPATION

Table - 7
Descriptive Statistics based on the variable Occupation

		N	Mean	Std. Deviation	Std. Error
Consciousness about Disabled Child	Academicians	123	171.85	32.61	2.94
	Rehabilitation Professionals	72	168.64	36.33	4.28
	Administrators	77	190.14	26.80	3.05
	Total	272	176.18	33.24	2.02
Consciousness about parents' perception	Academicians	123	184.92	26.57	2.40
	Rehabilitation Professionals	72	176.99	40.01	4.72
	Administrators	77	194.97	17.65	2.01
	Total	272	185.67	29.49	1.79
Consciousness about caring in action	Academicians	123	192.11	28.02	2.53
	Rehabilitation Professionals	72	180.42	42.74	5.04
	Administrators	77	196.78	27.69	3.16
	Total	272	190.33	32.96	2.00

Table - 8
One Way ANOVA for Occupation

		Sum of Squares	Df	Mean Square	F	Sig.
Consciousness about Disabled Child	Between Groups	21417.425	2	10708.712	10.360	.001
	Within Groups	278052.105	269	1033.651		
	Total	299469.529	271			
Consciousness about parents' perception	Between Groups	12164.434	2	6082.217	7.321	.001
	Within Groups	223482.121	269	830.789		
	Total	235646.555	271			
Consciousness about caring in action	Between Groups	10666.182	2	5333.091	5.057	.007
	Within Groups	283698.373	269	1054.641		
	Total	294364.555	271			

It can be seen from the preceding table that occupation has a significant impact on the level of consciousness towards the disabled child, parents' perception, and consciousness about caring action. Respondents whose occupation is administration have the higher level of consciousness towards

the disabled child, parents' perception, and consciousness about caring action. It can further be observed from this table that contrary to this the rehabilitation professionals have lower levels of consciousness.

INTERACTION EFFECT

Table - 9
Descriptive Statistics for Education and Occupation

	Gender	Education	Occupation	Mean	Std.Deviation	N
Consciousness about Disabled child	Total	Graduates	Academicians	148.03	32.24	40
			Rehab. Professionals	161.03	43.20	38
			Administrators	190.87	20.35	15
			Total	160.25	38.37	93
		Post Graduates	Academicians	182.45	26.27	38
			Rehab. Professionals	180.52	24.79	21
			Administrators	188.05	30.22	39
			Total	184.27	27.53	98
		M. Phil/PhDs	Academicians	184.07	26.10	45
			Rehab. Professionals	171.69	24.31	13
			Administrators	193.22	24.95	23
			Total	184.68	26.14	81
		Total	Academicians	171.85	32.61	123
			Rehab. Professionals	168.64	36.33	72
			Administrators	190.14	26.80	77
			Total	176.18	33.24	272

Table - 10
F- Ratio for Interaction Effect (Education*Occupation)

Source	Dependent Variable	Type III Sum of Squares	Df	Mean Square	F	Sig.
EDUCATION * OCCUPATION	Consciousness about Disabled Child	12884.841	4	3221.210	3.530	.008**
	Consciousness about parent's perception	3551.640	4	887.910	1.266	.284
	Consciousness about caring in action	3605.961	4	901.490	.900	.465

From the above table it can be inferred that education and occupation jointly have an impact on the level of consciousness about the disabled child. Administrators with higher education levels

have higher levels of consciousness about the disabled child. Evidently and concretely, based on the analysis of the data as mentioned above, this further dovetailed as below.

S.No.	Name of the Scales	Name of the Factors
1	Consciousness about Disabled Child	Educational Status and Occupation
2	Consciousness about parent's perception	Educational Status and Occupation
3	Consciousness about caring in action	Educational Status

As can be seen from the above description, the scales that seem to be pertinent are Consciousness about Disabled Child, Consciousness about parents' perception, and Consciousness about caring in action, resulting in factors leading to Educational Status and Occupation, significant at a .01 level.

FINDINGS

In India, gender has an impact on the level of consciousness, but it is limited only to the parent's perception. Interestingly men have higher level of consciousness as compared to their female counterparts, who have a nurturing and caring role, and carry the burden of household responsibilities including the care of the disabled child.

Education has a major impact on all the dimensions but it does not exhibit direct correspondence. Post graduates have the higher level of

consciousness as compared to their graduates as well as their M. Phil/PhD counterparts. Its impact is first to increase the level of consciousness and then let it decline. The fact or of close relationships with persons with disability has been highlighted by number of researchers who indicate that individuals who had more contact with persons with disabilities were more positive about people with disabilities than those who had less contact (Chan et al, 1988; Chan, Lee, Yuen, & Chan, 2002; Chen, Brodwin, Cardoso, & Chan, 2002; Gething, 1992). Persons who were more knowledgeable about disabilities through university training and professional practices held a more favorable attitude than those who had less knowledge (Chan et al., 2002; Gething, 1992; Hunt & Hunt, 2000).

In the category of occupation, interestingly, administrators have the highest level and rehabilitation professionals have the lowest level

of consciousness. It is desensitization, or it is a coping method, or it is a burnout effect, which may be working in the case of rehabilitation professionals. This is an important question to be investigated in the future.

Education and occupation jointly have an impact on the level of consciousness about the disabled child. Administrators with higher education qualifications have a higher level of consciousness about the disabled child.

As the attitude of society has a large impact on the level of independence of persons with disabilities, the study suggests that consciousness about the conditions of disability should be developed among the common public irrespective of educational qualifications and occupation. The extent of positive attitude of a society contributes to the betterment of a living atmosphere for persons with disabilities, leading them to an independent life. In summary, conscious development of the right attitude towards persons with disabilities, their parents, their living styles, etc., would contribute to their independence.

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Parent's Column

Susan LaVenture, Editor

To *The Educator's* Readership

The Parent's Column intends to help you keep aware of the marvelous work that parents' associations are doing around the world by sharing their news, events, programs and the latest developments of publications and website resources. Many of these programs that are offered by parents' organizations can be great resources for your regions. We also intend on inviting parents to submit their thoughts on the given theme of each issue of *The Educator* by sharing their points of view by including them in the "Parent Perspectives" section of this column.

The theme being Independent Living for this issue has a very interesting and meaningful perspective from parents that I think is important for professionals to hear. As parents we worry about our children and sometimes overprotect them or do too much for them whether they are blind or not even more so when we have a child who is blind and/or with special medical considerations. When raising children, parents have the challenge and responsibility to promote independence in their children and to make sure that their children learn the skills in each stage of their lives so they can meet those milestones from birth into adulthood. Parents need to have the instinct and knowledge to determine when to introduce and help their child learn a new skill and when to let their children try on their own and to move forward without help.

In my experience meeting with hundreds of parents of children with visual impairments

and from my friendships with adults who are blind - some parents have had a tendency towards low expectations for their blind children if they have not had the opportunity to meet other families that are seeking to learn more or to meet successful adult role models who are blind. Parents' associations have played an extremely important role in helping to support and educate parents about the possibilities for their children and encouraging them to have expectations for their children to succeed at whatever level they can - whether their child is high achieving or if their child has multiple disabilities, there should be expectations for achieving goals and milestones. As parents today have more access to information through the internet and as parental support and education resources are becoming more developed than before, I see its impact being more parents having expectations for their children to become productive citizens and lead fully engaging lives.

Please enjoy reading these parent perspectives from three families who have been very involved in learning about their child's visual impairment and its impact on learning how they have helped to encourage their child's independence: a mother's perspective from raising her daughter who is totally blind and from the perspectives of two fathers for promoting independence with children who are visually impaired with multiple disabilities.

Parent Perspectives on Independent Living

My thoughts

Gayle Skinner

Mother from Australian Parent's Association

It's important for parents to have the forward view and expectation that their visually impaired and blind children will live independently and are completely capable of doing so.

It has been easy for me because my daughter, though blind, always wanted to be like everyone else so she led us - her parents - along. We assumed that our daughter would be a fully functioning citizen, working and living in the community, not being looked after at home by her ever aging parents. But we had to be mindful that we had to teach her skills that our other kids learned by watching and following. We let her have a try at doing what she wanted. When she suggested riding a bike by herself, we kept our "no" thoughts to ourselves and planned ways for this to happen. She would need a wide space without obstacles, such as an oval/sports ground, we would have to run along behind yelling "go left, or veer right!" to guide her. Later I taught her to drive our gear-shift car, just like her sister and brother. Another example was when she wanted to cook from a young age so we gradually built up the skills. She can find the ingredients and the equipment. Yes, it can be a messy business but the more practice she got, the more skilled she became. From early teens, she has been cooking roast dinners and

spaghetti meals for the family and making scones, cakes and biscuits from scratch.

We expected that she would keep a tidy bedroom and clean the bathroom occasionally and do the dishes. This is what adults in the real world do - (well we're still working on her sighted brother!!) And so we spent the time teaching how best to do these things. At times the Occupational therapists at camps would show aspects of this self care, but it is important for parents to continue with the teaching and keep the expectations there.

My daughter can do anything. She just may do it in a different way. After bungee jumping, flying alone internationally, skating, tap-dancing, cooking, cleaning and even shopping for herself, it's no surprise that she has lived in her own flat for the past three years and supervises her household, organizing flat mates to pull their weight.

It is important for parents to foster that expectation that this is a normal progression for any child. They grow up and move out and fend for themselves. That's what we as parents are bringing them up to do. And we are doing our wonderful children a disservice if we handle it any other way.

A Father's Perspective on Independent Living

Paul Manning

Executive Officer, Parents of Vision Impaired, NZ

Yes, independent living is a lofty aspiration for our children, regardless of disability. Factor multiple disabilities into this ideal, and we have a real opportunity for the recipe to go astray. Ingredients needed for a successful outcome could be:

- Prepare families for the knowledge that independent living is achievable for their children. This preparation needs to commence in partnership with parents/families with a

focus of allowing **parents** to **drive** the process **with** their **child**. The process is not to be driven by well-meaning service providers.

- Allow time for parents to grieve and get used to the idea of letting go. Letting go on our terms (parents) is more likely to achieve a successful outcome.
- Ensure there is adequate funding and resourcing for parents and children; this information should be freely available and accessible in appropriate formats.
- Value the process of partnership with families, ensure this process allows families to remain families and not become service provider watch-dogs.
- Key ingredients could be: TRUST, RESPECT and COURAGE

I write this as a parent contemplating the above with our own daughter. We (Marie and I) keep coming back to a semi independent living arrangement for our daughter Jessica. We are being constantly challenged to let go; we are trying

to be brave and display much courage. Respect for our decisions and Jessica's are there but we do not have the funding to achieve what we wish; the only real option is to pay someone else to look after our child. This process here in New Zealand is very poorly funded and there are many instances of neglect and poor service delivery etc. Hence we wait, keep Jessica at home, but are working at changing current residential options at a national level - changes that work with families, not against them.

We are conscious of the effect this workload has on us as parents, and on our family, but to place Jessica in what we call a limited independent living environment and one that sees her financially crippled, we believe she is better off at home for the moment.

For us it is about changing attitudes to better reflect the needs of Jessica and her family. Once we achieve this, the above ingredients will exist, and we as families will have real choices for our children - choices that are healthy ones.

Independent Living ... just a reflection

David and **Rhonda Heather**, Parents from New Zealand

Our son Richard is now 36 and was born with Congenital Rubella Syndrome (CRS) in the brutality of the early 1970s. We were told he was a vegetable, would not crawl, walk, talk, lock him away and get on with your life. Semi independent living in 1971 was not a subject one talked about.

Richard had his first taste of semi independent living when he was about 18 and the change has been great both for him and Rhonda and me. For the vegetable that wouldn't walk, crawl, talk, etc., well, he just returned from a week at a challenging

outdoor pursuits centre in the mountains of the North Island, and loved it. His caregiver is still recovering!

Because of Richard's various disabilities he still requires continuing support but the degree of independence grows. We still remain the back stop, catcher and advocates and we are not allowed to die until at least 2075. We are awaiting a detailed report and recommendation on a further step to a new model of care that will extend his independence.....watch this space!

New Website Launched for Parents of Children with Visual Impairments

This spring the National Association for Parents of Children with Visual Impairments (NAPVI) USA and the American Foundation for the Blind (AFB) launched a new website for parents of children with visual impairments www.FamilyConnect.org. Please check it out and register online for free!

The Board of Directors of the International Association for Parents of Children with Visual Impairments (IAPVI) convened in Germany

The Board of Directors of the International Association for Parents of Children with Visual Impairments (IAPVI) convened their Board meeting in Hanover, Germany on July 16, 2008. The meeting was held in conjunction with the countrywide German Vision Conference that was organized by the Verband der Blinden-und Sehbehindertenpadagogen und -paedagoginnen e.V. (VBS). The organizing committee of the VBS conference invited IAPVI to present a workshop in Germany on "Parents Mobilizing Parents". IAPVI offers an open invitation for parents you know in the region that may want to communicate with us. Contact susan.laventure@perkins.org for more information about the IAPVI parents' meeting and workshop.

Philippine Parents Association to Host 2nd Congress

Parents Association for the Visually Impaired (PAVIC) Philippines will be hosting their 2nd Parents Congress on September 26-28, 2008. For more information about the conference program and registration contact, pavic_phils@yahoo.com

First International Family Conference to be held in Costa Mesa, California

The National Association for Parents of Children with Visual Impairments (NAPVI), United States hosted the first International Family Conference; Families Connecting with Families for Parents of Children with Visual Impairments in Costa Mesa, California on July 17-19, 2009. For more information about the conference log onto www.napvi.org

New Zealand Parents Petition the NZ Ministry of Education

Parents of Vision Impaired New Zealand Incorporated (PVINZ) has launched a petition to the Ministry of Education in New Zealand to fund in the 2008 budget to support a considerable increase in staffing numbers of Resource Vision Teachers.

We welcome news from parent associations and parent perspective articles for the Parent Column. Please send submissions to susan.laventure@perkins.org



Report from **Deafblind International**

Since we met for our World Conference in Perth, Western Australia last summer DbI Officers and its Council have been working hard to establish the priorities in our new strategic plan. With agreement from members to develop our Networks and Information function and focus more closely on staff development and advocacy there is a lot to think about!

Membership is also an issue, and with around 58 corporate members in 25 countries, we are seeking to both support established membership and reach out to new organisations and individuals. A timetable is being prepared and working groups set up to consider the issues and start things moving forward in a structured and manageable way.

Collaboration with ICEVI

At our recent meeting of the management Committee and Council we received a paper from Larry Campbell outlining some of the areas where collaboration would be fruitful.

We unanimously agreed to collaborate with ICEVI in the Education for All Global Campaign (EFA-VI) and will do this by creating a small group of specialists to respond, as appropriate, to EFA-VI initiatives. Our strategic group working on advocacy will also engage with EFA-VI ideas and activities.

In addition there is a proposal that our Secretariat functions have more contact with each other. We warmly endorse this very positive proposal.

DbI events

- We have a number of network and staff development events happening this year. “Co-creating communication with persons who are congenitally Deafblind” is taking place in Leeds, UK, in October. The scientific programme will be based on the work of the DbI Communication Network. (conference2008@sense.org.uk)
- Bergen, Norway, is the venue for the 7th Seminar of the Acquired Deafblindness Network. The theme is **“Activity, ability and participation: in all stages of life”** (www.deafblindinternational.org)
- A family event will take place in Glasgow, Scotland in August. It’s called “Listen 2 Me”. Lots of creative activities will be on offer to participants from all over Europe in the new TouchBase resource centre. The programme has been developed with the help of families and deafblind people and there will be opportunities to learn, share and have fun during the week. (info@sensescotland.org.uk)

Do come and join us if you can!

Eileen Boothroyd

DbI Information Officer

eileen.boothroyd@sense.org.uk



Visually impaired athletes make final preparations for Beijing 2008

Blind and partially sighted athletes from all over the world are in the final stage of preparations for the Beijing 2008 Summer Paralympic Games, where they will compete for medals in many of the sports on the Paralympic programme.

The Paralympic Games open on Saturday 6th September and will run until Wednesday 17th September. In total four thousand athletes from three disability groups (visually impaired, people with physical disabilities and people with cerebral palsy) representing 150 countries are set to participate in 471 events in 20 sports. Around 30,000 volunteers will be recruited for the games.

Along with IBSA's world championships, the Paralympic Games represent the pinnacle of any visually impaired athlete's career. The Beijing games, the 14th in the history of the Paralympics, promise to be among the best in terms of organisation and facilities, providing an ideal setting for athletes with disabilities to showcase their talent and skills before spectators and television audiences.

IBSA has three sports on the programme specifically for blind and partially sighted athletes:

Futsal / Five-a-Side Football

The world's six best teams will gather for a competition that is scheduled to conclude on the same day as the closing ceremony. World champions Argentina, Great Britain, South Korea, Spain and hosts China will attempt to defeat reigning Paralympic champions Brazil in the search for the gold medals. The competition is open only to totally blind players.

Goalball

Goalball has been a fixture at the Paralympic Games since making its debut in Toronto, Canada, in 1976. The female competition in Beijing will feature eight teams, including world champions Canada, China, USA, Denmark, Germany, Japan, Brazil and Sweden.

Twelve teams will take part in the men's tournament:

Pool A : Lithuania, Slovenia, Denmark, Spain, Finland and Belgium

Pool B : Sweden, USA, Canada, Iran, China and Brazil

World Champions Lithuania and Paralympic Champions Denmark are the teams to beat.

Judo

Blind and partially sighted judokas will compete against each other in 6 weight categories in the female competition and 7 in the male competition. 84 men and 48 women, making a total of 132 athletes, are set to participate. Men's judo has been on the Paralympic programme for many years and women made their debut at the 2004 Athens games.

In addition to the three VI-specific sports, blind and partially sighted athletes will compete in events in athletics, swimming, equestrianism, sailing, rowing and cycling.

For more information on blind sports, visit www.ibsa.es or contact ibsa@ibsa.es

For more information on the 2008 Beijing Paralympic Games visit <http://en.beijing2008.cn/paralympic/>



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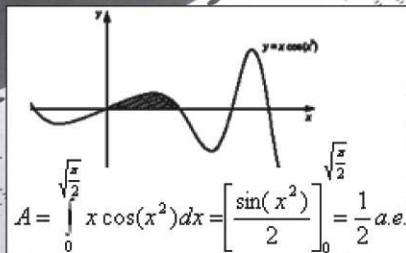
INDEX
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INDEX
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