

The Educator



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Parent Involvement



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**The International Council for Education of
People with Visual Impairment**

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Paul, we miss You



“What is beautiful never dies but changes forms”

Dear Paul

ICEVI is saddened that you are no longer with us. Though you were part of the Executive Committee for a brief period, you won the heart of every member. Your passion for the parents' movement made you a world leader, and parents' organisations emulate your selfless service and compassion for the cause. ICEVI is ever grateful for the dynamism you showed in your tenure as the regional chairperson of the Pacific region. You are the first parent who became the regional chairperson of an ICEVI region and this has really inspired other regions to bring parents on board.

You have shown us what grit, determination and courage really mean. You will always be with your family, your colleagues in the ICEVI, other colleagues all over the world, and people with disabilities. You are a silent but steadfast supporter guiding us from beyond.

You were a lovely person, and you gladdened the lives of people. Your memory shall continue to do so.

All officers of ICEVI express their deep condolences to your bereaved family who is in our prayers.

May your soul rest in peace.



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People with Visual Impairment**

Global Campaign on Education For All Children with Visual Impairment (EFA-VI)

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CONTENTS

01. Message from The President	02
02. Message from The Guest Editor	03
03. Parents of Vision Impaired New Zealand: Carrying on the work of Paul Manning - <i>Paul Heather</i>	04
04. European Award to Lea Hyvarinen	06
05. Parents Power: Ensuring a Better Future for Our Children - <i>Maria Rowena R. Fernandez</i>	07
06. Making Education Accessible: The Power of a Parents' Association in Israel. A historical Supreme Court of Justice (SCJ) ruling puts an end to decades of neglect and discrimination - <i>Guila Seidel and Yael Weisz-Rind</i>	09
07. WBU-Asia Pacific Regional General Assembly 2014	13
08. Advocacy Among Parents A Mother's Presentation at the WBU-ICEVI Joint Assemblies, Bangkok, 2012 - <i>Angelette Akkermans</i>	14
09. Families as Teachers—Social Competence Starts at Home: Childhood Reflections of Employed Adults - <i>Kathryn D. Botsford</i>	16
10. Expectations and Realities - <i>Kay Alicyn Ferrell</i>	29
11. PAVIC Parents Congress	31
12. IAPVI - Founded at ICEVI World Conference, Kuala Lumpur	33
13. For Parents by Parents "The Knowing" - <i>Paul Manning</i>	34
14. Parents' Perspectives on Self-Esteem, Braille and Independent Living	35
15. National Family Conference 2015 - <i>Susan LaVenture</i>	37
16. Global Action Week (2014) - Statement from Africa	38
17. Global Action Week (2014) - African Experience - <i>Martin Osangiri Okiyo</i>	40
18. Global Action Week (2014) - Kickoff Event in India - <i>Bhushan Punani</i>	42
19. Here and There	43

Guest Editor : **Susan LaVenture**, Executive Director, NAPVI. E-mail : laventures@lighthouseguild.org

Our International Partners





Message from The President

Dear Readers,

News has just reached us that Aubrey Webson, our editor, has been appointed Antigua's Ambassador to the UNITED Nations. This is a tremendous honour, and I wish to lose no time in sending Aubrey our heartiest congratulations from ICEVI. It is also a tremendous achievement and a well merited recognition of the huge store of experience and wisdom that Aubrey has to bring to such a role. This is great for Aubrey, great for Antigua and great for disabled people, whose standing will be enhanced by Aubrey's occupation of this role. There will obviously need to be changes at Perkins and in the editorship of *The Educator*, but we hope we will not lose touch with Aubrey, who still has so much to give to our movement.

This issue of *The Educator* is dedicated to the Parents' Movement - the movement of parents of visually impaired children. Before I go any further, can I say how much we mourn the death of our dear friend Paul Manning, who, as a parent himself, was such a passionate supporter of the parents' movement, and who served as the Regional Chairperson of our Pacific region for all too brief a period. During his induction as the regional chair in Bangkok in November 2012, Paul noted with emotion that this was the first time in the history of ICEVI that a parent had become the chair of one of ICEVI's regions. The entire Assembly echoed his sentiments by affirming that parents are important stakeholders in the work of ICEVI and pledged continuous support for the growth of the parents' movement throughout the world. I have been deeply touched by the fond memories of Paul and his contribution to the parents' movement to be found in the articles which follow. Our deepest sympathy goes to Paul's family, and ICEVI is pleased to dedicate this issue as a tribute to his work with partners and educators.

ICEVI was instrumental in forming the International Association for Parents of Children with Visual Impairments (IAPVI) at its world conference held in Kuala Lumpur, Malaysia, in 2006. Since then we have been working through our regional chairs to promote parents' activities wherever possible. I am delighted to be able to tell you that our regions have organised more than 100 capacity building programmes for parents in the last 6 years and our work will continue in the future to strengthen our ties with parent bodies. As earnest of this, we have introduced a column exclusively for parents in ICEVI's official journal, *The Educator*, and parent organisations are invited to share their

experience with readers through this dedicated column. We are also inviting Susan LaVenture, the indefatigable President of IAPVI, to attend ICEVI Executive Committee meetings to help maintain our focus on how parents and teachers can work together in bringing a better tomorrow for children with visual impairment.

In the current issue, you will find scholarly articles on this subject written by parents and professionals from different parts of the world. You will also find references to ICEVI's activities, in particular our participation in Global Action Week (GAW) in May 2014. ICEVI, as a member of the Inclusive Education Task Group of the International Disability and Development Consortium (IDDC), undertook a number of initiatives to celebrate this week and you will find a special report about the activities organised in our Africa and West Asia regions. We will continue to raise awareness of disability issues in mainstream organisations so that education of children with disabilities becomes an integral part of the general education system.

I am also happy to be able to tell you that preparations are underway to organise the WBU-ICEVI Joint Assemblies in the USA in 2016. There has been a slight hiccup in finalising the venue, but this will be resolved soon and we will be able to share this information with you through the October 2014 E-News.

You will be aware that, due to the Ebola epidemic, it has not been possible to convene ICEVI's Executive in conjunction with the IDP Africa Forum in Kampala, Uganda, in October, when we had also intended to re-launch our EFA-VI initiative. The Forum has been rescheduled for next May, but we will be watching the situation closely to see if these new dates can be maintained. We very much want to hold our meetings in conjunction with the Forum, but if this proves to be impossible, we will make alternative arrangements for our ICEVI meetings. In the meantime, I hope to be able to give you a stock take on how things are with ICEVI in upcoming issues of *The Educator* and our E-News.

Once again I take pride in ICEVI's involvement in the promotion of parents' activities and I congratulate all the writers and the Guest Editor on putting together such an excellent issue.

Colin Low
President, ICEVI



Message from The Guest Editor

We are pleased to share with you The Educator's July 2014 Special Issue on **"Parent Involvement"**, with articles written by parents and parent associations from around the world. The authors share their perspectives and information about how they helped improve education and services for families locally and nationally.

You'll read about OFEK (National Association for Parents of Children with Visual Impairments) and its long struggle for accessible education in Israel. OFEK appealed successfully to the Supreme Court of Justice, and now the Ministry of Education must provide alternate-format text books and teaching materials. In the Philippines, PAVIC (Parent Advocates for Visually Impaired Children) actively advocates for their children, provides support to their families, and promotes partnerships with social institutions, including Resources for the Blind, Inc.

These stories show the significant role parents play in their own children's lives and the impact they can make collectively through the advocacy of parent associations. These are just two examples of such stories from around the world. The World Blind Union (WBU) Children's Network conducted a survey to identify associations of parents of blind and visually impaired children from around the world. They received responses from parent groups in 35 countries, all eager to join our Network of International Associations of Parents of Children with Visual Impairments. Internationally, parents of children who are blind or visually impaired, including those with additional disabilities, share an emotional bond: the need to understand how visual impairment

will affect their children's development, and how to ensure that their child receives the appropriate specialised education. Parents need help to rear their children with visual impairments—emotional support, education, and connection to resources.

Kay Alicyn Ferrell gives vision professionals some powerful advice about our attitudes towards parents and their involvement in their children's education. Ferrell, ICEVI's North American/Caribbean Regional Chair, shares her interesting and frank perspective about working with families, drawn from her career in research on the early development of children who are visually impaired. Kathryn D. Botsford has researched adults with blindness, and her findings reveal "... the critical impact of parents' expectations on both the evolution of social skills and persistence to pursue paid employment."

ICEVI and the International Association for Parents of Children with Visual Impairments (IAPVI) dedicate this Special Issue on Parent Involvement to Paul Manning, Executive Director of Parents of the Visually Impaired New Zealand, who passed away this year. He was a loving husband and father of six children, one of whom was blind with additional disabilities. He was a strong parent leader in New Zealand, in ICEVI's Pacific Region, and one of the co-founders of the International Association for Parents of Children with Visual Impairments. He was a dear person who will be missed by IAPVI parent leaders and members from around the world.

Susan LaVenture

Executive Director, NAPVI,
Lighthouse Guild International, USA

Parents of Vision Impaired New Zealand: Carrying on the work of Paul Manning

Paul Heather, member and father of a son who is deafblind
PVI-NZ, New Zealand

The heart and vitality of any parents' support network revolves around the exchange of experiences, challenges, successes, and failures with our disabled children. The networking and support are quite a unique experience as families proceed on their journey.

Parents are neither heroes nor cowards, but ordinary men and woman who try to face the reality of their child's disability with determination and courage. We all remember well the shock we experienced upon learning of our child's disability, which most of us knew nothing about. Suddenly we were challenged to our very limits. In an instant we were expected to absorb a new reality and make decisions.

We began by asking questions and searching for information about our kids' disabilities. Confusion and frustration were common feelings, as we were advised by the medical profession, educators, social workers, rehabilitation specialists, and friends to treat the child like any other child. Much of the advice failed to address specifically the day-to-day realities of caring for our new arrivals. No one prepared us for the emotional and physical demands. No one told us that we might experience a period of grief as a result of not having the perfect child. No one told us that this might be a lingering experience, or indeed, might never go away.

We started on that rollercoaster of emotion that many of our closest friends and relatives could not understand. Some of us experienced fear, grief, sadness, and not always a lot of self esteem and confidence.

Sometimes we have been afraid to be honest about our feelings, worried about what professionals might think. We all need time to acknowledge, accept, and understand our child's visual impairment. In some cases it may take years to get a realistic definition of a child's condition, treatment, and future prospects, especially when the child has complex needs and several disabilities.

From this configuration of confusion and isolation our parent support network emerged. We found other parents and families and the sharing began. We experienced that instant engagement with another mother or father, who knew our emotions, our predicament, or our space. We found families who had solutions to problems we agonised over. We found families who could advocate, who could climb the odd bureaucratic mountain, who could beat down the professional "security" door.

Our parent group in New Zealand had its beginnings in 1983/84, when a small group of six parents met in Auckland for a weekend. We came away knowing we were all talking the same language. We all had the same dreams

and aspirations for our kids, and we agreed about the things we wanted to change.

So Parents of Vision Impaired New Zealand was born! In those early days we had a small grant from the Royal New Zealand Foundation of the Blind to produce a newsletter. This early support grew into substantial support. We employed an executive officer, formed a committee that could travel to meetings, and began the essential tasks of networking with other parents and advocating for our kids .

About fifteen years ago, Paul Manning joined PVI as the Executive Officer. Paul was a parent of a vision impaired daughter and he had a passion for the job at hand. He guided our organisation to many achievements during his tenure.

Paul often talked about the power of the parent network, about how our strengths and frailties come together to create synergies. He spoke of how we came from different pastures and backgrounds, and yet how easy it was to talk and relate. Indeed, it was easier than talking to our mates or our relatives.

Throughout Paul's leadership years we continued talking. We talked about the gatekeepers and who had the keys. We talked about the road blocks and where the detours were. Paul found the keys and the detours and opened many, many doors for parents, families, and our kids.

As an organisation we have participated fully in the development and growth of a new approach to education for New Zealand that is now regarded as an international model. Parents are represented in that forum, and as a result we have a very close collaborative relationship with the Ministry of Education.

In other sectors we have important relationships with the Ministry of Health, and the Ministry of Social Development. Twenty years ago we were spectators, today we are partners. Twenty years ago it was an adversarial environment, today it is a collaborative environment.

Paul opened many of these doors, while at the same time maintaining a special networking relationship with parents and families. When individual advocacy was called for he was available to answer the call.

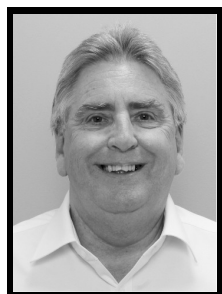
As Paul's network developed he became involved with parent support in the Pacific Islands and internationally. His experience and contribution in this forum was welcomed and appreciated. He reflected that like New Zealand parents, internationally we all seemed to talk the same language.

Regardless of our sons' and daughters' disabilities, our real job as parents is to harness all the confidence and courage we can and model that for our children. On this journey together we all need plenty of it. And in modeling it early on, we help our sons and daughters prepare for the day we won't be with them, except through the life lessons we have taught them.

On this journey, we will find many wonderful people who will make all the difference in our world. We will also encounter many difficult people and institutions and policies. When life becomes difficult, advocacy begins in a new way. The word advocate comes from the Latin *advocatus* which literally means "to call, or to answer the call to help another." This is the parent's task. This is the task that requires confidence and courage ... all that we can

muster. Someone once said, "In this life, trouble is to be expected. Misery, though, is optional."

As parents we need to be able to find those who can help in their best way and to establish our place of equality with them.



Paul Manning passed away in May 2014 after a long battle with cancer. He established a strong and vibrant parent network that will play a significant advocacy role for our parents and children well into the future.

Paul's favourite whakatauki (Maori proverb) is from "The Whale Rider" by Witi Ihimaera:

Kia hora te marino

Kia whakapapa pounamu te moana

Kia tere te karohirohi

I mua i tou huarahi

May the calm be widespread

May the ocean glisten as greenstone

May the shimmer of light

Ever dance across your pathway

European award to **Lea Hyvarinen**

on the 17 May during a ceremony organised by the TU University of Dortmund, Germany



For more than 40 years now, **Lea Hyvarinen** has been committed to people with visual impairment. She is one of the few ophthalmologists engaged in education issues. One of her outstanding capabilities is building bridges between medical professionals and special educators. From the outset she has contributed to various international and regional conferences of ICEVI with her lectures and workshops. She has developed a classification model in cooperation with ICEVI that observes the activities and functions in various contexts from the perspective of participation. She has worked

in all continents and in many countries and has taught and fought for the interests of children with special needs. Be it Africa, Europe, the Middle East or Asia - she is working, often hand in hand with the ICEVI, to change the structures of the medical and educational systems pertaining to visual impairment. Lea Hyvarinen has taught many professionals in special needs education and early intervention to trust in their own knowledge, integrating it with the specifications of ophthalmologists to improve the life situation of the children they both serve.

- Hans Welling

Former Vice-President, ICEVI and former Regional Chair, ICEVI Europe Region

Parents Power: Ensuring a Better Future for Our Children

Maria Rowena R. Fernande

President, Parent Advocates for Visually Impaired Children (PAVIC), The Philippines



PAVIC (Parent Advocates for Visually Impaired Children, Inc.) is an organisation of parents whose children have blindness, low vision or other disabilities in the Philippines. Our vision is that every child with visual impairments will enjoy equal opportunities and access in all activities in life, according to choice and ability. We actively advocate for our children by providing support to their families and promoting partnerships with social institutions. This work prepares parents to be better advocates for their children through awareness, acceptance, education, training and workshops.

PAVIC's programmes and activities for parents include seminars and workshops on acceptance, good parenting practices, and early childhood intervention. For parents of children with multiple disabilities and visual impairment (MDVI), we provide transition seminars. PAVIC helps in organising parents' support groups in different parts of the

country by providing leadership training. This includes fundraising strategies, livelihood training, and most importantly, informing them about the rights of their children. We have subsidised a therapy programme that caters to needy families. PAVIC's Parent Volunteering programme trains parents as teachers' aides, to ensure our children with visual impairment get appropriate attention and quality instruction in the classroom.

(Read more about it in the January 2013 issue of The Educator, pp.47-48:

<http://icevi.org/publications/index.htm>)

Most children with multiple disabilities and visual impairment need the intervention and services of therapists, who are extremely scarce in remote areas of the country. The absence of these services creates additional developmental and educational problems for many children. PAVIC conducts therapy skills transfer training for both parents and special education teachers to compensate for the lack

of therapists. (Read more about it in the January 2013 issue of The Educator, pp.45-46: <http://icevi.org/publications/index.htm>).

In May 2014, PAVIC held the Fourth National Parents Congress on Visual Impairment at the Bayview Park Hotel in Manila. We offer this Parents Congress every three years, at which we discuss concerns and issues identified the preceding year at the National Parents Consultation. This year's theme was "Ensuring Accessible and Quality Education". We focused on the programmes and services provided to our children by the government and other stakeholders, and on ensuring that our children will have a high-quality, inclusive education. We invited knowledgeable speakers from the government and non-government sectors. The event was attended by 148 participants; 80 from the National Capital Region (NCR); 44 from Luzon: 12 from Visayas and 12 from Mindanao.

The impact of the Congress will extend across the Philippines, increasing PAVIC's momentum for national change and providing increased sustainability to programmes. We hope to establish partnerships with other parent

groups, strengthening the national and regional networks of people advocating for their children. The Congress produced a position paper about parents' perspective on inclusive education in the Philippines, which will be presented to concerned agencies: Department of Education, Commission on Higher Education, TESDA, National Council on Disability Affairs, and other stakeholders. We are working on an action plan for collaborating with other agencies and government officials.

The parents' congress has been made possible in partnership with Perkins International, Lions Club International Foundation (LCIF), and International Council for the Education of People with Visual Impairment (ICEVI); and in collaboration with the National Council on Disability Affairs (NCDA), the Department of Education and the Resources for the Blind, Inc.

PAVIC also has activities to promote public awareness, including the annual White Cane Day Celebration on August 1, and our yearly March sports event named VISTA (Visually Impaired Sports Training and Advocacy), where we partner with both government agencies and Non- Government Organisation (NGO).



Dr. Suwimon Udampiriyasak (second from left), Regional Chair, ICEVI East Asia Region with the PAVIC office bearers

Making Education Accessible:

The Power of a Parents' Association in Israel

A historical Supreme Court of Justice (SCJ) ruling puts an end to decades of neglect and discrimination

Guila Seidel and Yael Weisz-Rind

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This article is dedicated to late Paul Manning, an inspiring parent and a true friend.

For more than 60 years, the state of Israel neglected its obligation to make education accessible for children with blindness or visual impairment. The Ministry of Education (MoE) refused to provide school books and materials in accessible formats or allocate budgets to address the need.

Parents were referred to the Central Library for the Blind, the only institution that provides accessible reading materials to the community. Although not supported by the MoE, the Library made efforts over the years to respond to the demand, but suffered from lack of funding and production capacity. It could only provide part of the books, especially when complex translation processes and unique expertise were required. For example, only two or three math books were translated every year. Furthermore, the formats provided were mainly in audio format, with very few Braille books. And so, parents were forced into a complicated process – struggling to compile book lists from schools in advance and obtain school materials, preparing Braille books, reading to their children and generally spending hours to support their child's learning.

For many parents the demand of time, resources and work was an impossible task. This unbearable situation had a grave impact on children who could not reach their full potential and fulfill their talents. In the Israeli context, wherein all the children who have only visual impairments (no other disability) are in mainstream schools, and where resources are limited, this was even more critical. In many cases students dropped out of school or were forced to abandon certain subjects due to lack of books.

Ofek Liyladenu (Hebrew for Our Children's Horizon) is Israel's National Association of Parents of Children with Visual Impairments. The organisation was instrumental in bringing about a dramatic change. The association's long-term advocacy work produced the solution to this frustrating situation and promoted the children's right for equality in education.

The Road to the Supreme Court of Justice (SCJ)

Since its establishment in the late 1990s, Ofek Liyladenu has represented the children and parents in discussions with the Ministry of

Education and other authorities. The organisation advocated for equal educational rights for children with visual impairments, but met with no success. In an attempt to put pressure on the government, we recruited support from many Knesset members (the Israeli Parliament). They tried to promote the issue through Questions to the Government, discussions at the Education Committee and the Committee on the Rights of the Child, and lobbying. Yet, the authorities remained indifferent. The government consistently refused to take responsibility and shifted it on to the parents.

At that time, a survey among the parents revealed a grim picture of desperation and exhaustion, which confirmed our understanding of the need for a different approach. At this stage the board of Ofek Liyladenu took the decision to escalate our actions and explore the legal avenue. In our search for legal advice and support we approached Bizchut, the Israeli Human Rights Center for People with Disabilities. Bizchut is dedicated to enabling people with physical, intellectual, sensory, mental and learning disabilities to participate as fully and independently as possible in the life of the mainstream community. The name "Bizchut" (by right in Hebrew) reflects the belief that all people are entitled to the same rights and that the needs of people with disabilities must be met on the basis of entitlement rather than from a charity-based perspective. Bizchut provides legal representation on principle issues and they agreed to represent Ofek Liyladenu in this case.

The process included setting up a steering committee composed of parents with children

of school age who were willing to be the petitioners. This was not an easy task, since many parents feared that their children would suffer repercussions from the establishment. In the preparation process with the committee, other areas of inaccessibility were identified. These included teaching materials other than books, such as internal school worksheets and exams.

The committee also identified the great problematic situation with matriculation exams, where the student with visual impairment could not sit the exam in real time. While their sighted peers started the exam, they had to wait for a support teacher to translate it into Braille, which could take up to few hours, and all this time they were not allowed to leave the exam room. When finally able to start the exam, they often finished hours after their sighted friends due to the waiting time and the additional time allowance accorded to students with visual impairment. For example, in a multiple choice exam, they had to wait for the full translation of all the questions before starting to answer. As a result, it was not uncommon for a Braille-reading student to finish the test up to eight hours after other examinees!

The committee's conclusions and the needs it identified were discussed with Bizchut's legal advisor. The stakeholders decided the best strategy was to appeal to the Supreme Court of Justice. Another hurdle in the process was the ongoing formulation of accessibility regulations which took place at this period. We submitted our requirements but had to wait for their completion before assessing whether the children's needs are fully addressed. Once the process was completed, we learned that

the regulations do not refer to the right to equal education of children with visual impairments through provision of accessible books. In November 2011 the Appeal was submitted to the SCJ.

First Achievements

Before the court's first scheduled hearing on the case, the state made a dramatic announcement, accepting its fundamental responsibility to provide accessible books. For the first time in Israel's history, funding was guaranteed in the Ministry of Education's budget to produce school books in one of four formats: Braille, audio recording, digital format and enlarged print. The SCJ instructed the MoE to open a dialogue with the association in order to address the acute needs of the children. In the months that followed, the MoE launched a process to systemise the production of the books, and established communication channels with Ofek Liyladenu.

Groundbreaking Success

The SCJ considered the issues and disputes and made its formal ruling in December 2013. The landmark ruling's main points are:

1. The Ministry of Education (MoE) recognises its **responsibility to provide accessible text books, teaching materials and matriculation examination** to children with visual impairment.
2. Accessibility is provided in a **modular way**, in four relevant formats: Braille, enlarged print, digital file and voice recording. The student should be able to **use any of the formats as well as any necessary combination according to their needs**.
3. Providing **internal school materials is the responsibility of the school** via the relevant teacher.
4. **MoE regulations on schools' obligation** to ensure accessibility of internal materials and school activities will be **published by 1/3/2014**. The MoE will consult Ofek Liyladenu on the regulations and will refer to the four formats and to the procedure through which a decision is made on the suitable formats. The regulations will include criteria for providing voice recording.
5. **Accessible matriculation examination** – the MoE recognises its responsibility to provide exams in either Braille, enlarged print or digital file **in real time**. The MoE will publish a regulation on the interface between the school and the Examination Department regarding the matriculation examination for students with visual impairments.
6. **Timing of book distribution** to the students: the MoE position was that books will be provided by the end of October, two months after the beginning of the school year (for books included in the MoE lists by May). The MoE also noted lack of qualified professionals to produce Braille books in mathematics in Arabic, and thus, when necessary the teachers will be responsible for assisting the students until the books are provided. Our position was that all books should be provided at the **beginning of the school year** (end of

August). The court ruled in favor of our position.

7. Use of **digital files**: the ruling referred to the need to amend Israel's Copy Rights Law 2007 which was already in discussion in the Knesset. The proposed amendment is set to decriminalise the act of providing a copy of a publication to people with visual impairment or other reading disabilities, regardless of the publishers' consent. Thus, the ruling noted that the State will ensure that this amendment is **prioritised** so that all school books are accessible in digital format for children with blindness and visual impairment. In the interim the MoE will act to ensure all publishers' consent for the use of a digital file by students with visual impairments, and will consider legal actions against those who refuse. If the MoE does not progress in timely manner on this issue Ofek Liyladenu can approach the SCJ again.

Finally, this court noted that the petition

raised a crucial public issue and the petitioners have a significant role in advancing the solution to the problem.

And since most of the petitioners' claims were accepted by the court the MoE will pay the trial costs of the petitioners.

Next steps

In spite of our great achievement there was no time to rest on our laurels. While the MoE demonstrates a better attitude--transparency and cooperation with Ofek Liyladenu, new challenges and difficulties arise in this transition period. These require our on-going follow up and involvement.

The challenges are on several levels:

1. The preliminary planning of the book production and distribution process by the MoE was not well structured, as it was the first time it was faced with such a task. The process includes many constituencies, service providers and complex procedures which requires an integrative approach. This was missing.
2. Lack of expertise, capacity and tools mainly from the service providers who were not ready for the large volume of demand and the expertise it requires.
3. Lack of communication with Ofek Liyladenu on the process and timeline. This was a major obstacle in the books production since the MoE missed the opportunity to learn from the rich knowledge and experience of the parents. Also, parents were not informed of the process conducted by the MoE, e.g., timeline of the books delivery, service providers, etc.;
4. Delays in publishing the MoE regulations and their communication to schools.

In the following months, we insisted on on-going feedback from the parents which proved to be crucial for us in our discussion and work with the MoE. The feedback was useful for improving the process, from the first steps of compiling reading lists through the production of the books and finally the timely distribution to the students. We expect that for the next academic year we will see a considerable improvement and an efficient system for the provision of accessible school materials.

"We are thrilled with the court ruling" says Yael Weisz-Rind, Executive Director of Ofek Liyladenu. "Children with blindness and visual impairments are no longer second class citizens and can enjoy their right for education and start the school year as their sighted peers".

Guila Seidel, Chairperson of Ofek Liyladenu, says, *"Now, our children can fulfill their potential and grow to be independent adults who contribute to society. All they need is the adequate attitude and support of the MoE and in their schools."*

Ofek Liyladenu is a non-profit association funded by donations. The association is a big, supportive, diverse community for more than 1,200 families from all parts of Israeli society, and provides services, support and representation to the children and their families.

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World Blind Union - Asia Pacific Mid-Term Regional General Assembly 2014

21-24 November 2014 Hong Kong

The World Blind Union - Asia Pacific Mid-Term Regional General Assembly 2014 will be held on 21-24 November in Hong Kong.

Globally, WBU is divided into 6 regions, with each region having its own Board to address the needs of the local members. World Blind Union-Asia Pacific (WBUAP) is one of the regions, and now has member organisations from 20 countries and 2 territories. WBUAP meets every 2 years, on the occasion of WBU General Assembly which is held every 4 years, and the WBUAP Mid-term General Assembly held in between.

WBUAP Mid-Term Regional General Assembly 2014 will be an opportunity to develop solutions to problems faced by blind persons in this region. There will be discussions on educational opportunities, access to information, employment and social enterprise. In addition, an exhibition of the latest technical aids for visually impaired persons will be held along with the event.

Date : **21-24 November 2014**

Theme : **Make the Right Real in the 3rd Asian and Pacific Decades of Persons with Disabilities, 2013-2022.**

Venue : **Cyberport 3, 100 Cyberport Road, Hong Kong**

Language : **English with simultaneous interpretation in Cantonese and Putonghua for the plenary sessions.**

Advocacy Among Parents

A Mother's Presentation at the WBU-ICEVI Joint Assemblies, Bangkok, 2012

Angelette Akkermans, Parent advocate, Mi ta stimabo, The Netherlands
E-mail : mitastimabo@planet.nl

Dear audience,

Good afternoon and welcome to this meeting. My name is Angelette Akkermans. I have been involved in the ICEVI since 2002.

I am very pleased that you are here and that you are interested in hearing my parent story.

I am the mom of a beautiful lady. My daughter is now 23 years old, and I always say she is beautiful outside and also inside. Laura is her name and she is a student of management economics and law.

Laura was born healthy, but after vaccinations in her infancy she developed rheumatics. Because of that she got uveitis, which is an infection in her eyes. She can see only light and dark with one eye, and the other one just 0.5, but she is doing reasonably well. She likes to study and to work but it costs her very much energy. She is now recovering from a burnout. She has to learn to say, "This is enough for today; no more; I must stop now." This is her lesson to learn, but I try to help her learn her limits.

Laura had very good amiable teachers and they supported her in doing everything she could. She likes to live on her own, with support from us, her mom and dad, and some help from others to clean her house.

We are here from many different cultures, but I think that every parent will recognise my story. I would like to share it with you to encourage others. We can work together and accomplish even more.

Most of you are professionals, and you are here at this conference with parents from the USA, Israel, New Zealand, and Malaysia. We urge you to tell the parents in your country that they are not alone. They are welcome to contact us at the international parent association.

Most people can't imagine what it means to have a child who is disabled. Your life changes when you enter into this new world. There are lessons to be learned, you have to recreate yourself on this road, and you have to get information. You must learn a language that differs from the one you are familiar with. On this road you will meet unexpected companions, people you never met before. It's actually a totally different world.

Everything is a little bit slower and differs from the life without disability. But this also makes your world bigger and more glamorous than you could ever have expected. After a while you begin to look around, and suddenly you notice that it is possible for you to live in this world. There are so many interesting things you come into contact with and can be

involved in, and so many interesting people you can work with.

Never forget you don't have to do this alone. Try to involve your family and your friends. You can talk about the problems and the successes you have. There are wonderful things to share! Never suppose that others know and understand -- tell them! It can be a tremendous pitfall if you don't! The pain that you feel will never, never leave you; these things will be with you for the rest of your life. It is the loss of your entire dream. But, please, don't spend the rest of your life grieving over the fact that you don't have a healthy child! Find people who are willing to reach out a helping hand and to cooperate with you. If you don't, you will never be free and you will never be able to open yourself up for the special and beautiful things that you will find on the way. Inclusion means to cooperate, to try to find out: what, why? The others (the helpers, the organisations) do things the way they have to do them.

Try to be deeply involved in this world—which is your world and your child's world. Find ways

to work with the people you find on the way, so that you will never ever have to say, "If only...." In the end you will be stronger and can be proud of yourself and your child. You enter a world you have never dreamt of. Believe in your strength as a parent; always follow your instincts, and above all always believe in the possibilities of your child. It's amazing!

Let us share our knowledge and our skills. By cooperating, we as parents can work with the professionals and the governments.

The generosity of the parents I have worked with is not limited to money; we have shared empathy, time, interest, and our experiences. This has empowered us and we urge you as professionals to reach out to your parent organisations. Together we can share the responsibility and support each other in this important work.

Please contact my Dutch organisation, Mita stimabo at mitastimabo@planet.nl. We will always get back to you as soon as possible. Thank you for your interest—let's work together!



Families as Teachers—Social Competence Starts at Home: Childhood Reflections of Employed Adults

Kathryn D. Botsford

University of Northern Colorado, USA

Introduction

Families, teachers and researchers know that their children with visual impairments need to learn the same social competencies as all children who leave high school, transition to college and/or work, and live fulfilling independent adult lives. On one hand the news is encouraging, with a 94% high school completion rate for students with visual impairments reported in the National Longitudinal Transition Study-2 (Wagner et al., 2005). However, despite many indicators of positive transition outcomes, employment rates for youths (ages 13 to 26 years) with visual impairments or blindness remain low: at around 30% (AFB, 2006; Shaw, Gold, & Wolffe, 2007). McDonnall (2010) compared employment rates for students with visual impairments at 38.2%, to those rates for youths in the general population at 72.6%. The impact ripples into adulthood with an employment rate of 36.8% for adults in this population (Erickson, Lee, and von Schrader, 2012).

Rationale for a social competence study

Families and teachers know that developing effective social skills has impact well beyond the classroom. Sacks and Wolffe (2006) cite social competence as critical for success in the workplace, home, and community well beyond

the school years. Golub (2003) interviewed managers who employ adults with visual impairments to identify the things that increased employee success. The results emphasised independence, individual achievement, the American with Disabilities Act, and social skills. Employers specifically identified conversation skills, good fit within the work culture, and “maintaining harmonious productive relations with fellow workers” as the social competencies needed by persons with visual impairments (Golub, 2003).

The theme of maintaining social harmony is also found in Ladd’s (1990, 2006) studies with children without disabilities, and creates a compelling argument supporting the need for all children to experience social acceptance in their lives. Celeste (2007) noted that “social competence must be a priority for children who are visually impaired” (p.521). By exploring the stories of people who are blind and who also have jobs, families, and independent lives, the current study was designed to help families and teachers understand the specific social skills youths need as they prepare to transition from school.

Methods and Procedures

Participants: Fourteen adults (8 males and 6

females) who ranged in age from 26 to 65 years (average age: 41.65 years) participated in this study. The people who shared their stories for this project lived in rural and urban areas from communities on both coasts and in the interior-western United States. While these questions were not asked as part of their interviews, participants also shared that they:

- ▮ identified as members of consumer groups (either the American Council of the Blind or the National Federation of the Blind);
- ▮ were in some type of personal relationship with a spouse or partner;
- ▮ lived independently as head of household either alone, with spouse, and/or dependent children.

Everyone in this study used the label blind to describe their level of useful vision. Some people were born with eye conditions causing blindness from birth, while others reported losing their vision in early childhood. All participants were employed in professional careers, identifying their workplaces as school (1); government (4); or a private agency serving persons with blindness (9; from four separate agencies). They reported their work status as employed or volunteering for a period of time ranging from 2 to 27 years (average years of employment: 13.36). Ten people identified themselves as having full-time paid employment and one had recently retired from full-time paid employment (78% total reported that they had full-time paid employment). Three participants (21%) worked as part-time volunteers. Eleven people were able to meet in three separate focus groups. Three requested individual telephone interviews.

Participants' educational achievement closely matched the information reported in large government databases like the NLTS2. Wagner et al. (2005) reported that 94% of youths completing the NLTS2 surveys had completed high school. In this qualitative study, 100% of participants had graduated from high school or had a GED. Ninety-three percent (93%) of this study's participants reported they attended university or junior college after high school. The 2009 NLTS2 summary reported that 78% of the survey respondents with visual impairments who were recent high school graduates had gone onto some type of college (National Longitudinal Transition Study 2, 2009). Of the people who shared their stories for this study, 78.5% had some type of college degree.

Data collection: To find participants, I initially contacted state and private rehabilitation programmes for the blind. Agencies then identified potential participants who met the study criteria: blind from birth or early childhood, braille readers, ages 18 to 65, and employed for a minimum of 1 year. People working part-time or as volunteers were also included. Agency contacts told potential participants about the study and asked people who were interested to contact the researcher directly. The study documents (consent and survey forms) were then emailed to participants prior to the interviews so they had an opportunity to access the materials through their preferred reading medium.

Focus groups interviews were the preferred data source for this study. Face-to-face meetings were conducted at the convenience of the participants. Participants selected all

locations based on their own time constraints, balancing work and family obligations, as well as their experiences with those settings. Three individual interviews were coordinated based on the time and travel constraints of the participants.

Researcher background: I am a teacher of the visually impaired (TVI) and orientation and mobility specialist, with over 15 years experience working with children and youth with visual impairments and their families. I am not blind myself, but in my job I help students and families make decisions about how to prioritise which skills to teach children as they progress through school, graduate, and move into their adult lives.

Prior to conducting the focus group and individual interviews, I asked two adults who are blind to help review my interview questions, because they have direct experience using social skills to facilitate professional relationships. We worked collaboratively to refine the final set of questions used for interviews and focus group discussions.

Theoretical model: The phenomenon of viewing people with disabilities as needing more support, or different standards, than non-disabled persons is longstanding. According to political scientist Barbara Arneil (2009), the social and political tradition of overprotection can be traced back to political thought from Judeo-Christian European traditions. In this view, persons with disabilities are seen as deviating from ideal image of God: at worst somehow deficient, at best needing different social rules (Arneil, 2009). There is a well-entrenched perception that naturally

occurring diversity equates to deficiency, necessitating a separate (and less rigorous) set of standards, expectations, or treatment. Reframing this perception requires a new theoretical perspective.

This theme was part of the phenomena of social competence as expressed by participants in the current qualitative study. Steve, a study participant, summarised Arneil (2009) in a discussion contrasting gender and blindness. He pointed out that adults with blindness are expected to accept the unwanted assistance of family and even strangers:

Yes, you as a sighted adult would not have to do that because the sighted community sees another—sees you as a sighted person, so you don't need any help. You're not a baby to them. Basically, I think the sighted community thinks of the blind as "our child," so we need to protect them. And if you're not above them or on the same playing field as them then you need the help.

Study participants cited low expectations (93%) and overprotection (57%) as barriers to developing appropriate social skills.

In her essay on feminist disability theory, Rosemary Garland-Thomson (2002) noted the appropriateness of applying critical inquiry theories to disability research as part of a broader tradition of identity studies. She proposed this as a way to expand discussions of disability beyond topics of health and medical services. Garland-Thomson proposed to transform feminist theory by expanding the discussion, recognising that, as with gender

difference, naturally occurring biological variances were socially and politically defined.

By exploring how disability, like femaleness or gender, is defined in terms of deviating from the social construct of normal, Garland-Thomson (2002) reframed perceptions and more accurately placed disability within the broader spectrum of human difference.

The stories of both male and female participants reflected the sense of psychological growth. At the same time, they expressed distress upon encountering stereotyping based on misconceptions about blindness. In his story about returning home to his family after finishing college and a programme in independent living skills, Chris reflected on the conflicts created in his family as he tried to establish himself as an independent adult:

In my situation I was changing. I was learning to be independent and learning to speak up for myself. I remember having an issue with using my cane with my family because I used to just take someone's arm and we'd go. They were comfortable with that, and like that way of doing it. Well -- when I started saying "no, I'm going to use my cane." "It's not that I don't love you. It was almost like this cane was a person. Like it was their rival. You know, a rival for their attention because they really got insistent [about acting as his sighted guides] sometimes. I'd say "It's a cane; it's supposed to help me". And, they'd say "no, you don't need that thing".

Results

The language of the participants lent itself to feminist disability theory as presented by

Garland-Thompson (2006) and Arneil (2009). This theory seeks to shift our perceptions of disability as some unnatural inferior state, an unfortunate event, or misfortune. "Rather, disability is a culturally fabricated narrative of the body, similar to what we understand as fictions of race and gender" (Garland-Thompson, 2006, p.5). In this study the researcher, a Teacher of the Visually Impaired, hoped to gain some insight into how employed blind adults approached their social interactions so that, in turn, she could be a better teacher for her families and students. The themes of the participant stories clustered around general issues of exhibiting polite behavior and basic good manners rather than the issues of learning disability adjustment skills or techniques. Some of the themes identified in these data support those previously reported in transition and employment research. The skills identified as facilitating employment outcomes include basic manners, having a sense of humor, putting others at ease with disability, reflecting corporate culture, being able to discuss accommodation needs, and requesting or refusing assistance (Golub, 2003, 2006). A new theme, participants' sense of group identity and the subsequent sense of responsibility as a member of a disability group, was reflected in 93% of the interviews in this study

The critical role of parents: When participants were asked to discuss where they learned about social skills, they identified parents, specifically mentioning the responsibility to both teach social skills and also to provide opportunities to practice those skills in naturally occurring interactions. According to both the data and the current

literature, “basic manners” was, by far, the most important social competence contributing to facilitating relationships and interactions at work.

When we met for this study, participant Jim immediately said, “It’s almost like you’re saying that blind people don’t have very good social skills.” Sara reminded him, “If a child is not taught how to be appropriate then they are going to be terrible and nobody will want to be around them. One of my students doesn’t have any social skills. He has no manners. He’s super intelligent but that’s not going to carry him anywhere.”

Jim’s initial reaction can be viewed through the feminist disability theory lens as the frustration of someone encountering stereotyping based on pre- or misconceptions of blindness, instead of being immediately viewed as a unique individual. However, Jim acknowledged that some parents make excuses for their children because of their disability. This recognition of differentiated treatment reflects the social and political development of disability as described in Enns (2010). Jim offered a powerful story that reflected the transformative power of viewing blindness as a biological difference and not as a social construct of inability. His story reflected many of the themes that evolved through this study:

I think social skills for blind people start at home. You have to be taught to be normal just like everybody else. You know there’s a lot of blind people who rock and poke their eyes and stuff like that, and it’s just not normal. Parents have to make you do everything that everybody else does. In my

house, you did not say can’t. If you said can’t you were in big trouble. Mom would wash your mouth out with soap if you said can’t or because. Because is not a word that you can use as an excuse. Unfortunately a lot of parents of blind kids overprotect their kids. They want to do everything for them, and they’re doing them an injustice. How are they [the kids] going to know how to do it if you’re doing it all for them?

Jim’s early childhood experiences emphasise the role parents have in socialising their children, whether or not a child has a disability. In this thematic thread, parents are the primary teachers of social competence for young children in two ways: setting expectations and providing opportunities for independent learning. In the broader data, 86% of participants cited the role of their parents and families as the primary teachers of social skills. A related theme, overprotection, demonstrates the power parents have in supporting and empowering their children to build experiences, self-awareness, and social competence.

Jana shared, “My parents [and] my family modeled politeness in everything and so, I really followed their lead ... and they taught me all that. And my mother always had this saying, if you use honey, you’ll get a lot further than vinegar and things like that.”

Fourteen percent (14%) of study participants who indicated learning social skills in a school setting also said that their families set behavioral expectations that reinforced those skills. In her own childhood story of attending a residential school, Sara reported that, unlike

Jim, she learned most of her social skills at school. But she was quick to point out that her parents supported the same behavior expectations at home. Although not directly stated, this discussion hints at an underlying societal or cultural expectation that schools, and teachers of children with disabilities, will set the tone for social skills instruction. However, as Sara pointed out, parents are the critical source of social skills instruction for their children. Schools and teachers alone cannot teach children to be socially appropriate.

I see that at work all the time. I have a variety of parents who are either extremely overprotective, and will not let their children experience a variety of things so they can grow socially, or they will pardon their students and say it's okay, he doesn't have to be polite: he doesn't have to eat like that if he doesn't want to. Then the child suffers because then they end up coming out with rude behaviors. If the school, or staff, or other folks this child interacts with try to correct it, and there's no consistency between the parents and the teachers, then it's really bad because the child is very intelligent and will know they can play one against the other. Just like they would play one parent against another.

Sara's reflection is complex and reflects the importance of viewing all human physical difference on a spectrum of normal. Sara's observation that parents hinder their blind children by setting different, and lower, expectations for social behavior is reflected in the stories of other participants. The importance of setting the same standard for

all people in society, especially blind children, was emphasised by 93% of study participants. Participant observations, and my professional experiences, show that schools and teachers have a role in supporting the family's expectations and values. It is also important to note that a teacher would be challenged to try to teach a set of social skills or expectations that ran counter to those espoused by a child's family. This is not to say that TVIs simply reinforce parents' expectations. The point is to emphasise the importance of working with families to build their understanding, acceptance, and investment in teaching basic manners and appropriate social skills to their children with vision impairments.

Opportunities and expectations: Along with 93% of participants emphasising the role and responsibility of families to set high expectations, 64% talked about the need for parents to provide opportunities for their children to have experiences in which they can learn appropriate social behavior.

But also, I think it's so important for the parents to reinforce that and expect their kids to do things, help out around the house. Don't be afraid to let your child use the stove if they've been taught how to use it because that will serve them well when they get older. I know we've had students here, and I've heard stories of students that have come in here that didn't know how to make a sandwich, you know.

And so, that is sad, but I'm sure the situation was that the parent always said, oh, it's just easier for me to do it; it will take me too long to show you, you'll make a mess. Well, yeah, they might make a

mess and it might take a while to teach them. But that's how you teach any kid. And it's going to do them far more harm if you don't teach them because they'll be, you know, 30 or 40 and they can't cut their steak or they can't make a sandwich or do whatever it is they need to do.

I think there seems to be this idea that parents don't think about the fact that they're not going to be around forever, they're not immortal. And so, more than likely, at some point in that child's life, they're going to be on their own. And if they haven't been taught the skills that they need to know, they're going to really be in trouble, and the parent won't be around to get them out of that trouble.

In 2004, Wagner noted “that students with visual impairments...who are in general education, as well as special education settings, can lack social competence” (p.1). This is despite decades of research and commercially available social skills curricula. While having a visual impairment appears to contribute to delays in social awareness, persons with vision impairments develop the capacity to perceive and appreciate others’ perspectives. Peavey and Leff’s 2002 study of high school students with visual impairments documented the power that sighted peers have in shaping the behavior of their peers. When these peers shared their reactions to observing socially atypical habits of their counterparts with visual impairments, four of the five study subjects with visual impairments took the feedback and changed their habits. Peavey and Leff’s (2002) findings were illustrated in participant stories about the

influence of school peers in developing appropriate social skills.

Reflecting on her own learning of appropriate social behavior, Jana’s memories of being a young child in her neighborhood school demonstrated the power of peer feedback. While the exchanges may sound unkind, Jana felt they helped her really see the impact of her behavior on others.

I have a couple of experiences that still stick in my mind from friends. When I was in first grade I used to eat with my mouth open. I wouldn't close my mouth. I was at lunch and my friend, one of my good friends, said to me, "You can't eat that way. That's terrible." I still remember it because I was so embarrassed and I never did it again [laughter].

And then another time, I didn't know that when you drink out of a drinking fountain that it's the stream of water that you -- you don't put your mouth on the edge of the drinking fountain because I didn't know that. And then I remember a friend then saying, "Oh, that's terrible. You know you can't be doing that." I think a couple of my friends were really instrumental, too in maybe stopping me in saying things and I would get my feelings hurt in a way, but then I would always change right away and make sure I would never do that again.

Work by Gurrette and Smedema (2011) and Nyman, Gosney, and Victor (2011) found that perceived overprotection by family and friends was both positively correlated to, and a significant predictor of, depression for persons with visual impairments. Cimarolli and

Boerner's (2005) descriptive study discovered correlations between positive social support (the perception that help from family and friend will be available) and optimal well-being. Negative social support (underestimation of one's capabilities or lack of support) was correlated with less optimal well-being. Participants in this qualitative study echoed the importance of their relationships with their families and the hurt they felt in encountering overprotection.

George, a 33-year-old man, emphasised that parent and family expectations and acceptance of blindness continued well into adulthood. George's story resonates with the findings in Gurette & Smedema (2011) and Nyman et al. (2010) in addition to reflecting the misconception and frustration threads.

Family can be part of the solution, but it's so easy for them to become part of the problem. I love a good steak dinner. Prior to getting my training at the center, I would always request that when I'd go home for Christmas or whatever. My mother cut it up for me because, you know, I'm "visually impaired." Then I came to the center and they're saying basically, "what on earth are you doing? Here's a steak knife, you use it yourself!"

I remember the first time I cut my own steak in a restaurant. It gave me this phenomenal feeling of independence! It's wonderful because it reemerges every time I have a steak now. It's just phenomenal. And the reason I mentioned this is because about two years ago, I happen to be sitting in a restaurant with my mother. And this is three or four years after training. Three

or four years of, you know, having these in-depth conversations with my mother regarding my blindness and how valuable I find independence and demonstrating it to her through daily actions, living my life, you know, being married at the time and everything. And I was sitting at a restaurant with her and I got a steak. And she offered to cut it up for me. And I remember feeling extraordinarily hurt. This was very emotionally upsetting for me; even gets to me a little bit now actually because I felt like I had been doing my utmost -- I thought we had very open, very clear communication about where I felt my independent skills were, that we were on the same page.

Appropriate behavior: One of the interview questions was, "What does the phrase 'being polite' mean to you?" The thread of basic manners occurred in 86% of the interviews. Other threads coded along this vein included parent expectations for behavior (93%), analysing social contexts (93%), showing respect to others (71%), considering the feelings of others (64%), and demonstrating appropriate behavior (57%), and managing activities of daily living, such as eating, dressing, grooming, personal care, and personal hygiene (50%). As a TVI, Sara discussed her experiences with students who lack basic manners, and her struggles with parents who considered vision disability as an excuse for a child's rude behavior. Jane, a 48-year-old mother and blindness rehabilitation instructor, shared a similar observation about expectations of appropriate behavior. Her story included threads that reflected the feminist-disability theory, in which disability is

a societal construct, not an innate state of being.

I see rudeness in my [blind] students as a personal issue. Working with the teenagers and young people that I work with, I don't see it as a disability-specific issue. Yes, I've seen a few young people like that young man who are visually impaired, but I've also seen it in people with cognitive impairment, people with other typical impairment and typically developing people of all ages. Unfortunately, I've even seen it in myself. So I think it's a personality issue.

The responsibility of social identity:

As a TVI, I have worked with families, schools, and students' peers to dispel stereotypes about blindness. Discussions with the people who participated in this study presented something I had never considered: a deep sense of social responsibility inherent in their identity as people with blindness. The awareness of some social identity as a member of a disability community, or that an individual's behavior reflected on the public's image of the larger group, was found in 93% of the participants' responses.

Discussions of accepting or refusing unwanted assistance illustrated this theme and reflected the significance of appropriate social support identified by Cimarolli and Boerner (2005), Gurrette and Smedema (2011), and Nyman et al. (2011). In the literature, accepting and refusing assistance is identified as a specific social skill valued by employers (Golub, 2003, 2006). When asked to reflect on her experiences with refusing unneeded or unwanted assistance from strangers or

colleagues, Sara reflected on balancing her own emotional reaction with a sense of social responsibility:

If somebody asks if you need assistance, or they make a comment to you out of ignorance, it is so hard to be able to emotionally pull yourself back together and be able to respond appropriately. But if you don't, and you want to go off on them and let them have it because what they said was not appropriate, the only thing that comes away from that whole conversation or interaction is, "blind people are so rude!" It never becomes about what they said. You know what I mean?

Even while acknowledging his frustration with encountering strangers' perceptions of him based on misconceptions of blindness, Jim also reflected on the sense of personal responsibility that keeps him from reacting negatively to unwanted "assistance":

If I do that to somebody and I'm totally obnoxious, which I can be, obviously (laughs), then what's going to happen if there's some blind person out there who is flailing and lost? Is the sighted person going to be more or less apt to help? I mean, hello? After some blind guy was just going off on 'em? They're not even going to want to talk to another blind guy.

Participants in this study reflected a heightened sense of responsibility influenced by their recognition that blindness is a low-incidence phenomenon. This included the realisation that an encounter with a stranger could be the experience that shapes

someone's perception of a blind person. Their discussion highlighted their sense of having to balance personal reactions to their social responsibility to other blind people. All participants mentioned the importance of educating the broader public about blindness. As independent, employed people involved in their community, this becomes a delicate dance in which they confront, and attempt to mediate, the common perception that a disability is a deficiency. All this while simultaneously striving to be seen, and appreciated, as a complex individual who transcends a stranger's preconceptions of a culturally superimposed identity: blind person.

Feminist disability theory emphasises that disability is just a social label and all human beings fall somewhere along a broad spectrum of difference. Participants in this study shared personal experiences reflecting that; if we want adolescents and youths with blindness to acquire the social competence needed to step into adult roles, it is critical to have the same standards and expectations of the child with visual impairments as we have for any other child.

Jim's story reflects the power of his parents' communicating to him that he was normal by holding him to the same standards as his non-disabled peers. Other participants discussed the idea of acting appropriately in a variety of social situations. When asked about his use of body language, Jim appeared confused by my question. He referred to his parents teaching him the behavior they expected of him. As a result, Jim has an ingrained motor memory of body language and posture. When asked about his use of "body language" to facilitate communication, Jim emphasised his reliance

on interpreting a speaker's vocal cues: tone, inflection, and cadence to interpret unspoken meaning. When I repeated my question about body language he acknowledged the benefit of understanding the social or contextual meanings of gestures or postures used by communication partners, but added:

I don't really think about my body language, to be quite honest with you. I mean, you want to sit there and just look normal, but other than that, I don't know. I guess I'm not seeing how other people's body language is, so I don't worry about my own. Obviously I don't want to be rocking back and forth or looking inappropriate or something like that, but other than that, I don't really worry about it.

The question reflected my subconscious view that someone with a disability might view himself, or the world, from a lens of difference. Jim's response reflected Garland-Thomson's (2002) proposal of disability as a societal construct. Jim only perceived of himself, including his posture and gestures, as normal. For Jim, the question was a non-issue; and therefore, confusing. Jim's response, that he didn't monitor his own body language, was an answer that one would expect from any confident and capable adult.

Conclusion

In this study, employed blind adults' experiences of the acquisition and use of social skills distilled into three major themes:

1. Families are the primary and most effective teachers of social skills.

2. Expectations and opportunities for authentic experiences and feedback are crucial building blocks for social competence.
3. Participants recognised that they are members of an identity group: people who are blind.

These themes echo previously reported findings around social competence in the workplace (Golub, 2003, 2006), and the psychological and emotional impact of encountering misconceptions about blindness (Cimarolli & Boerner, 2005; Guerette & Smedema, 2011; Nyman et al., 2010). Additionally, participant language supported the application of a critical inquiry theory to explore the interaction of people and their communities. Finally, this study reflected a previously unreported theme, that of a deep sense of social responsibility based on participants' identity as members of a disability group. This sense of responsibility had the power to positively influence individuals' responses when feeling frustration with the general public's misconceptions of blindness.

All participants expressed a sense of responsibility for educating people about blindness. This thread reflected a wide range of social competencies: social, cultural, and interpersonal sensitivity; using humor to diffuse awkward situations created by others' preconceptions or misconceptions of blindness; personal self-control; remaining calm, professional, and emotionally detached when experiencing stereotyping or discrimination; and a willingness to persevere or, in Jim's and Dan's words

"prove yourself", without becoming defensive or angry with strangers who are meeting a person with a visual impairment for perhaps the first time.

The people who shared their experiences for this study repeatedly emphasised basic social skills or basic manners as the techniques they employed most frequently and the skills they saw as most critical in creating positive social relationships. Jim, Jana, and Sara's experiences illustrated that all children, regardless of a unique physical characteristics, need to be allowed and encouraged to interact and establish positive relationships with their peers. This theme was reflected in much of the research on children with and without visual impairments, leading to the conclusion that peer acceptance is a universal need (Burhow et al., 1998; Ladd 1990, 2006; Ladd, Herald-Brown, & Reiser, 2008; Kef, 2005; Kef & Dekovic, 2004; Rosenblum, 1997, 1998).

As a teacher, Sara pointed out that basic manners were the key to social success, and emphasised that parents were the primary and most critical teachers of these skills. She stated that families shortchange their children when they don't set the same behavior expectations for their blind children, when they don't teach or expect basic manners, when they use disability to excuse a child's rude or hurtful behavior, and when they don't provide their children with opportunities to experience the world or independently explore social relationships. The children suffer because they're denied opportunities to develop a level of social competence alongside their peers.

Implications for Families and Teachers

The results of this study emphasised the primary and critical role parents have in preparing their children for adult roles.

While I had hoped to discover specific instructional strategies to use with students, the stories collected for this study showed that the most effective role of the TVI would be to reinforce the values and behavior standards set by their students' parents. Based on the memories and experiences of these employed adults, the takeaway is that while schools and teachers are important sources of information about low vision and blindness, they are not the most effective primary teachers of social skills for these children.

Specifically, teachers can help families understand their critical role in (a) setting and communicating high expectations for social behavior, and (b) providing opportunities for blind children to practice a variety of skills in the community. For TVIs, this means working closely with families, learning family cultures, and encouraging families to set high standards for their children, especially those who are blind or visually impaired. In participant's stories of learning social skills, the successful teacher's role was less about direct instruction in compensatory strategies, and more about empowering parents to be confident about their abilities to teach their own children.

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Expectations and Realities

Kay Alicyn Ferrell, ICEVI North American/Caribbean Regional Chair
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Professionals recognise the importance of parent involvement in their children's education. But do we recognise the importance of allowing parents to choose their level of involvement?

Generally, people who are planning to start a family do not think about their child being visually impaired or having any sort of disability. We expect our child to be perfect – the brightest, most beautiful, best looking, most talented, most accomplished child that was ever born. Only with time do we realise that maybe our children really do not meet our early dreams of perfection. We love them regardless, and we have great pride in each and every one of their accomplishments. As professionals, we should bring the same acceptance and understanding to the families that we work with.

Educators often seem to base their opinion of families on how involved the parents are in their child's education. Do they welcome home visits, no matter how many people? Do they attend parent-teacher conferences? Do they volunteer in the classroom? Do they hold office in parent groups? More often we hear comments like, "She loses so much over the weekend/vacation/school holiday." "His parents just won't follow through," or "They never attend parent meetings." We sometimes forget that we are not "on" all the time, that we like some time off, and that leadership has different meanings at different points in time.

Children with visual impairment move in and out of various placements according to their

changing educational needs. The continuum works both ways: students might begin their schooling in an inclusive classroom, then find they need a more intensive placement to develop specialised skills. Or a student might move from a specialised classroom to an inclusive classroom once those specialised skills are in place. Even then, the student might move back and forth along this continuum of school settings, depending on the amount of additional support needed and the demands of the curriculum.

Similarly, there is a continuum of parent involvement, much like the continuum of educational placements. Parents will move up and down along this continuum depending on what else is going on in their lives. For a year or two, home visits may be welcome, but after a while they could seem like intrusions, especially if there are multiple home visitors because of the child's complications. As their child moves through school, they might change their level of involvement depending on their child's needs. At some point, a parent might want to lead a local, state, or even national organisation; at other times, a parent might want to retreat from the intensity of always thinking about – or being defined by – his or her child. Another child might need attention. Or a spouse might need support and encouragement. It might not fit with our expectations for what the parent of a child with a visual impairment should be doing, but it certainly fits with the realities of everyday life.

Professionals have their own continuum of participation. We hold an office in a professional organisation, and we're glad when our term is over. We mentor student teachers, then we don't want to do it again for a while. Our own children need our attention; our spouse demands more of our time. We run out of money and cannot travel; we are diagnosed with a chronic illness; we are just plain tired. Parents of children with visual impairment are no different.

We expect parents to do the things that we do, even though we are the ones who went to school and earned degrees in order to work with students with visual impairment. We chose the profession of educator, and we chose to teach infants, children, and youth with visual impairment. Parents – in most cases – did not choose this work that we love.

In Reach Out and Teach (2011), I outlined 15 rights that all parents have, but which I felt were particularly important to parents of children with visual impairments. These are not legal or civil rights, but they are expectations that should guide our interactions with families. These are just as important for parents to remember as they are for professionals. Parents and families have:

- | The right to ask questions.
- | The right to seek another opinion.
- | The right to privacy.
- | The right to say NO.
- | The right to ambiguity.
- | The right to feel angry.
- | The right to keep trying.
- | The right to stop trying.
- | The right to set limits.
- | The right to be a parent.
- | The right to be unenthusiastic.
- | The right to be annoyed with their child.

- | The right to time off.
- | The right to be the expert-in-charge.
- | The right to dignity.

To paraphrase what I wrote then: these rights boil down to the right to be respected and treated as an equal. In every situation, parents should expect to be neither pitied nor admired. Parenting a child with visual impairment is different, but it is no more worthy of admiration than it is of pity – it is simply different. Parents should expect to be listened to and supported in a nonjudgmental way. Parents expect the truth—from doctors, teachers, social workers, and therapists who are there to help; from friends and neighbors, who owe them a chance to be someone other than “parent-of-a-disabled-child;” and from family members who might be encountering someone with blindness for the first time. Parents deserve to be talked to as an adult.

Our expectations often run headlong into reality. The truth is that we are more likely to develop the kind of parent involvement we want if we understand that parents are facing the same day-to-day realities that all people – including us – encounter. Those realities fluctuate for a variety of reasons, many of which might be unrelated to the child with a visual impairment. Parents will respond as they are able and as frequently as they are able. And if they do not, it is not an opportunity to judge as much as it is an opportunity to support, think creatively, and problem-solve.

Being invited into a family's home is a privilege, regardless of the geographical location or the culture. Let us remember to treat parents the way we would want to be treated ourselves.



PAVIC Parents Congress

- Report from the organisers

History

In 2002, some members of Parent Advocates for Visually Impaired Children in the Philippines participated in the ICEVI International Conference. Inspired by what they learned, they proposed that PAVIC organize its own nationwide parents gathering. The goal was to provide the opportunity for parents from various regions to compare their experiences as they work to ensure full educational rights for their children with visual impairment.

In 2005, PAVIC organized the first Parents Congress with the theme, “Working for a Brighter Future”. Parents discovered that their children are generally denied access to quality education. They got strength from one another at the conferences, knowing that they were not alone. The idea of a national parents’ movement had strong endorsement from the International Council for Education of People with Visual Impairment, Christoffel Blindenmission, Perkins International, and Lions Club International Foundation. It also gained support locally from the Resources for the Blind Inc., Lions MD-301, Department of Education, and the National Council on Disability Affairs.

Since the first Congress in 2005, PAVIC has held a national parents event in Manila every three years. Among the prestigious speakers were Professor Michael Stein, Executive Director of Harvard College Project on Disabilities; Ms. Deborah Gleason, Program Officer of Perkins International; Ms. Loretta Ann Rosales, Chairperson of the Commission on Human Rights, and Ms. Susan LaVenture, President of the National Association for Parents of Children with Visual impairments (NAPVI).

Ensuring Accessible and Quality Education - Conference in 2014

PAVIC’s 4th Parents Congress was held on May 9 -11, 2014 in Manila and the theme was ‘**Ensuring Accessible and Quality Education**’.

Among the speakers were school administrators who are supportive of inclusive education for visually impaired students from elementary through high school and tertiary levels. Various government agencies explained their roles as inclusive partners. Access to Information Technology, low vision services, and rehabilitation service information drew great attention among the participants.

Parents were divided into 4 groups for concurrent sessions that included seminars and workshops: Blind/Low Vision, MDVI/Transition, Deafblind, and Higher Education. Parent participants came away with action points, more insights, and determination for the road before them.

The keynote Speaker, Dr. Suwimon Udompiriyasak, Chairperson of the ICEVI East Asia Region, introduced the scope of ICEVI's international work and its impact on regional development. She invited parents to be part of the Global Campaign on Education For All Children with Visual Impairment(EFA-VI).

Key learning experiences and recommendations of the Conference

1. All parents learn to accept their children with disabilities. They fully understand that their children have equal rights to rehabilitation and education. It is the obligation of government parties at all levels to ensure that these rights are respected. Fortunately, the Parents Congress has become a forum where various government agencies introduce their policies and programs, which enhances communication with parents.
2. All parents know that their children can develop to their full potential with appropriate intervention and education. Active participation of parents in these processes greatly improves the students' quality of life.
3. Parents are urged to learn how to advocate effectively for their children. Working with school administrators and teachers ensures greater learning opportunities and better school experiences. Parents gained insights for advocating within the system.
4. Parents expand advocacy with other NGOs and local civic groups for financial and logistic supports. We gained not only sympathy, but involvement of people in the communities working for the betterment of children with special needs.

Parent Power

- + All Regions, except ARMM, had representation in this 4th Parents Congress.
- + About 80% of the participants were housewives. These parents are equipped and ready to work for a better community for their children.
- + This 80% parent-housewives roughly represents the situation all over the country.
- + When properly trained and channeled, parents' involvement improves the lives of children with disabilities.

International Association of Parents of Children with Visual Impairments (IAPVI) Founded at ICEVI World Conference in Kuala Lumpur

(Published in the January 2007 issue of The Educator)

By **Susan LaVenture**, Executive Director
National Association for Parents of Children with Visual Impairments, Inc. (NAPVI) (USA)

The International Council for the Education of People with Visual Impairments' world conference held in Kuala Lumpur, Malaysia this summer provided a forum for parent leaders of national parents' associations and parents who are interested in being a part of a parent community to convene. The parent participants were intrigued with the overall conference aims; to promote dialogue at the highest level on international issues reflecting the theme of the conference "Equality in Education: Challenges and Strategies", to facilitate an exchange of perceptions, experiences, practice and research, and to provide a current international overview of the equality of access to education and rehabilitation for children and young people with a visual impairment.

With the growing participation and interest of parents attending ICEVI World Conferences that began in Sao Paulo, Brazil and continued into the Netherlands, the ICEVI Program Committee had the foresight to support the momentum by including a Focus Day workshop on "Parents Mobilizing Parents for Advocacy" to be organised by experienced parent leaders, Paul Manning, Executive Officer of the national parents' association in New Zealand, PVI, Guila Seidel, founding president of the national parents' association in Israel "Ofek Liyladenu", and myself representing NAPVI the parents' association in the United States. Each parent leader shared their experiences in leading and organising national parents' associations and the impact these associations have in their prospective countries for changes and improvements in the delivery of services and policy in health, education and welfare for children with visual impairments. The purpose of the Focus Day was to encourage the development and organisation of parent associations and their ability

to mobilise positive changes and improvements within their own countries. Because the conference was in Asia, parents mainly from the Philippines, China, Malaysia were able to attend; other parent representation was from Netherlands, Denmark and England. There was rich dialogue and interaction amongst participants of the parent meeting. One of the points of discussion was the realisation by observation at the ICEVI conference; parents do not have an "international parent voice" in facing global issues. As a result the international parent leaders formed the first founding governing Board of the International Association of Parents of Children with Visual Impairment (IAPVI) and presented the following Resolution that was accepted at the ICEVI General Assembly:

Resolution

"It is hereby resolved that in order to enhance and facilitate the work of ICEVI and the Global Campaign, ICEVI hereby endorses its partnership with the newly established "International Association of Parents of Children with Visual Impairment (IAPVI)" and the formation of parent organisations in every country. The ICEVI Regional Chairs are hereby asked to collaborate with IAPVI and other such organisations in their regions, so that all regions are represented."

The main purposes for the newly established IAPVI will be to encourage the development of parents' associations and to be a representative voice for parents on international issues that impact the education and welfare of children with visual impairments and their families. IAPVI looks forward to collaborating with members and partners to fulfill the goals and objectives of ICEVI's Global Campaign.

Parents of Vision Impaired (NZ) Incorporated

(This letter was written by Late Paul Manning and published in The Educator - July 2007 issue. This letter is printed as a tribute to Paul)

May 2007

For Parents by Parents

"The Knowing"

Greetings to you all,

I have been given this wonderful opportunity to regularly write a column for "The Educator". As a parent of a child with complex needs, this is a wonderful opportunity. First I would like to introduce my family to you. I have been happily married to Marie for 33 years, and together we have 6 children, 5 daughters and a son, and 3 wonderful grandchildren. I am a lucky man! Our 4th child Jessica has special needs.

The first two years of Jessica's life were a living hell for us all. Jessica was born 3 months prematurely and weighed 800gms..... Marie and I were only just coping, no, we were not coping. It was horrible. No-one understood how we were feeling. Another parent advised us to attend a weekend meeting of parents called Parents of Vision Impaired. We were encouraged this would help. You will be amongst friends, amongst parents who understand. I thought. "What have we to lose, anything will be better than what we are going through at the moment". I went, and they were right. I returned home changed, inspired, and with hope - hope for Marie and I, hope for Jessica. I learned that education for Jessica was not a dream but a reality that she will go to school and learn just like her sisters. I also learned how to cry and not feel ashamed etc. I felt passionate for the first time about Jessica's future.

Some 23 years ago, a small group of parents approached the Royal New Zealand Foundation of the Blind (RNZFB) seeking seed funding for an annual meeting of Parents raising Blind and Vision Impaired (V.I.) children in New Zealand. 3 years later Parents of Vision Impaired NZ was formerly constituted.

One needs to be very clear why parents value coming together. The commonality of shared experiences of their Blind or V. I. children is a very strong bond. Parents learn, inspire and empower each other when given opportunities to be together. Here in New Zealand I call it "the knowing". The ability to connect and understand where another is coming from cuts across many cultures. It gives natural authority to speak without fear of judgement, without fear

of having to explain, of being listened to. It is an acceptance that for many of us we find very healthy. Some explain it is as a "fix" like no other.

For many years, PVI NZ existed successfully as a voluntary parent model. As the PVI membership grew it became necessary to become more professional. We decided to employ someone, a paid position that would move the organisation forward etc. Looking back this has been our single most important undertaking. We urge other developing parent groups to follow this path more quickly than we did.

Today PVI NZ is seen as a credible parent organisation in our country. We work collaboratively with our educators and health officials at local, regional and national levels. We now work in the International arena through the ICEVI/WBU EFA - VI global campaign.

Here in New Zealand, we have an education network called BLENNZ (The Blind and Low Vision Education Network of New Zealand). BLENNZ has been a joint venture with our Ministry of Education, Resource Teachers Vision, the Royal New Zealand Foundation of the Blind and PVI NZ. It has one employer, one set of national standards and guidelines ensuring consistent work practice. Although BLENNZ is still in its infancy, we are expecting in the Government Budget announcement further allocation of funding and resources. I shall explain more in the next issue; hopefully it will be good news!

Please support parents in your communities to come together and learn from each other. Let them learn at their pace. Let them be "for parents by parents". Self-determination is a wonderful thing providing it takes people with it.

Until the next time, take care.

Best Wishes

Paul Manning

Executive Officer, Parents of Vision Impaired NZ Inc

Parents' Perspectives on Self-Esteem from Around the World

(Published Columns from the past issues of The Educator)

Self-Esteem is about parents letting go and having the confidence to allow their children to try what they want to try. Parents need to be brave enough to allow their children to have a go – within reason, of course – but you can't minimise the activities of your children because they are blind or VI. Be confident enough in your child to support and encourage them to have a go at lots of different things.

Parents need to have a well-developed sense of self-esteem too. They need to accept that they have their child's best interests at heart and did their best even if mistakes were made or they missed things.

Don't beat yourself about the head because of hindsight showing what you could have done. Learn from it and be more open next time.

About helping VI kids, find ways to do things rather than stopping them because they can't see. My blind child has ridden a bike by herself, driven a car – with a co-driver, been taught to drive the family car just like her siblings, began cooking from about age 8/9, did a tap dance solo at the concert.

It's about de-briefing when things don't go the way they were expected to and finding a new way to tackle it or accepting that it may not happen – building resilience to bounce back.

- Gayle Skinner

President of the Australian Association for
Parents of the Visually Impaired

Children with visual impairments need to have self-esteem. Good self-esteem is important because it helps our children to feel proud of themselves and what they can do. It gives them the courage to try new things and the power to believe in themselves. For instance, we have a visually impaired boy who has developed the skills in identifying different models of cars just by touching the outer shape and design and sometimes by the sound of the engine. Each time he is able to identify correctly there is a victorious smile on his face and he is indeed very proud of his achievements.

He then develops the courage to try and learn to identify other models of cars, MPVs and 4WDs. This experience has had a positive effect on his relationships with others. He is able to relate to new people quite easily and often enjoys their company. Having good self-esteem is also to build-up confidence level for a visually impaired child. The child will be less likely to follow the crowd if his/her friends are doing something which is not right. He/she will be smart enough to make his/her own decisions.

- Alvin Teoh

Parent Leader, Malaysia

Parent Perspective on the Importance of Advocating for Braille and Encouraging your Children to Use Braille

Angelette Akkermans

Dutch Organization from and for Visually Impaired People and their Family

In Holland we are also celebrating the 200th anniversary of Braille. As a parent of a visually impaired child, I always feel like an ambassador of the right to read and to learn, and to get information in the form you can read. Since 2000, I've been the counsel for special (adapted) books; this means all kind of books and all kinds of information.

My visually-impaired child is now 19 years old. It is important that we as parents always stay alert, even when our children are as old as mine, because most of the services offered by the government are developed by people who do not know anything about visual impairment.

At this moment in Holland we have free school books for children in high school. However, the parents of children with visual impairment have to pay for the special books. We have written to the government telling them that there is a law on equal rights and what needs to be developed.

We always keep advocating for our children. We have also been giving information to members of the Government, caring organisations, etc. about what it means to have a visual impairment, and what can be done.

We are telling them that a lot of things are possible, and that I as a parent like to be regarded as an equal partner. Let them stand on a podium, or have a picture in the newspaper, knowing that we did it together.

We always have to believe in the possibilities of our children. In Holland we have a very great mom. Her name is Dorine in het Veld. She and her blind son Tim are great. They have among other things got mathematics on the agenda in Holland and Europe. See her website (www.dvelop.nl) or send her an email to talk about your problem. May be she knows a way to handle it.

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!

National Family Conference 2015:

National Association of Parents of Children with Vision Impairments

International Guests are Invited to Join Us in Chicago in 2015!

Susan LaVenture, Executive Director

National Association of Parents of Children with Visual Impairments, (NAPVI) USA

I'm pleased to announce that the next NAPVI National Family Conference will be held in Chicago, Illinois, USA on July 10-12, 2015. Lighthouse Guild and NAPVI will provide a worthwhile experience for families, so please do share this news with families within your countries. International guests are welcome to participate in the program.

The Chicago Lighthouse for People Who Are Blind or Visually Impaired has generously offered to host our conference. They're located in the Chicago Medical District on the campus of the University of Illinois at Chicago (UIC), which is only three blocks from the conference hotel site.

We've got a NAPVI discount room rate of \$169 per night at the Chicago Marriott at Medical District/UIC. We will be in the Chicago neighborhood called Little Italy, which boasts over 50 restaurants and bars within walking distance. For those of you who would like to explore Downtown Chicago, it's just a short cab or train ride away.

Our conference will allow you many opportunities to meet and learn from other families and professionals in the vision educational and medical fields. The children's program promises to be active and fun for all ages. We hope that you and your families will join us.

Please visit www.lighthouseguild.org or contact the NAPVI National Office for conference program updates at Napvi@lighthouseguild.org.



NAPVI

National Family Conference

National Association of Parents of Children with Visual Impairments

SAVE THE DATE



July 10-12, 2015 • Chicago, Illinois, USA

Location:

Chicago Lighthouse for the Blind
1850 W Roosevelt Road, Chicago, IL

Conference hotel:

Chicago Marriott at Medical District/UIC

Visit lighthouseguild.org
for conference updates.

For more information contact Susan LaVenture, Executive Director NAPVI
at laventures@lighthouseguild.org

EQUAL RIGHT

EQUAL OPPORTUNITY

Education and Disability

Global Action Week (2014);

Equal Right, Equal Opportunity - Inclusive Education for Children with Disability

Statement from Africa

The International Council for Education of People with Visual Impairment in Africa celebrates the 2014 Global Action Week (GAW). The theme for this special event is Equal Right, Equal Opportunity – Inclusive Education for Children with Disability. ICEVI's nine African Focus Countries are also participants in the Global Campaign on Education For All Children with Visual Impairment (EFA-VI), in partnership with national coalitions on education. These partners are local Global Campaign for Education (GCE) representatives, national associations of the blind, EFA-VI nodal agencies, other DPOs, and respective Ministries of Education. ICEVI is also a member of the Inclusive Education Task Group of the International Disability and Development Consortium (IDDC).

It is ICEVI's mission to promote equal access to appropriate education for all children and youth with visual impairment. We envision a barrier-free educational environment in which these students may achieve their full potential. In line with this mission, we urge International Non-governmental Organisations, including UNICEF, UNESCO and UNDP, National Non-governmental Organisations, CSOs, and especially national education coalitions, to ensure that children and youth with disabilities access quality education in barrier-free and inclusive environments. This goal is supported by the proactive pronouncements of the United Nations Convention on the Rights and Welfare of the Child (CRWC) and the Convention on the Rights of Persons with Disabilities (CRPD).

ICEVI acknowledges these facts:

- 1) 15% of the world population that live with some form of disability faces a myriad of challenges to equally and fully participate in society. In particular they are denied their right to education, which in turn hinders other rights, therefore denying them a chance to contribute to national development.
- 2) There are 161 million persons worldwide who live with a disabling visual impairment, of whom 37 million are blind and 124 million are persons with low vision.
- 3) At least 4 million people with visual impairments or blindness are preschool and school-age children.
- 4) 80% live in developing countries.
- 5) Less than 10% of these children are receiving education.
- 6) The girl child with visual impairment receives less attention and is doubly discriminated against.
- 7) Almost none of the growing numbers of visually impaired children with additional disabilities receive any educational services.

ICEVI therefore joins the Global Campaign for Education and other partners to call for:

- 1) Creation of appropriate legislative frameworks, and ambitious national plans for inclusion. All governments must ratify and implement the CRPD, CRWC and the Marrakesh treaty that facilitates access to published works for persons who are blind, visually impaired, or have print disabilities.
- 2) Provision of capacity, resources, and leadership to implement ambitious national plans on inclusion. Governments must ensure their Ministries of Education are backed by high-level political leadership and have the primary responsibility for the education of disabled children. Different levels of responsibility must be clearly outlined across the whole education system. At least 20% of national budgets should be allocated to education, and at least 50% should be dedicated to basic education.
- 3) Improvement of data on disability and education, which builds accountability for action. Governments must ensure education data is disaggregated by disability and gender, and that it tracks both enrolment and retention (including in different schools, such as segregated or mainstream).
- 4) Making schools and classrooms accessible and relevant for all. Governments must provide accessible materials and assistive technology to support learning, and develop and enforce accessible school building regulations.
- 5) Ensuring there are enough appropriately trained teachers for all. Governments must reduce teacher-pupil ratios, so that teachers can focus on individual learners' needs, and must ensure adequate pre-service and in-service training in inclusive education.
- 6) Challenging of attitudes which reinforce and sustain discrimination. Governments must tackle the attitudes which keep children with disabilities out of schools by launching an awareness programme among parents, children, communities, schools and within the public sector.
- 7) Creation of an enabling environment to support inclusive education, including cross-sectoral policies and strategies that reduce exclusion. Governments must bring in additional policies and resources to support inclusive education for children with disabilities, i.e. social protection schemes, Community Based Rehabilitation Programmes, Early Childhood Care and Education (ECCE), or health programmes.





Global Action Week (2014) - African Experience

Martin Osangiri Okiyo, Regional Coordinator, ICEVI Africa Region

ICEVI engagement

1. In the African Focus Countries, ICEVI engaged national associations of the blind (which are its national representatives) to influence the Global Action Week (GAW). This year's GAW, with the focus on education and disability, has seen tremendous improvement in networking and collaboration between these associations and other partners in the disability and development sector. The partners shared their experiences and expertise with the Global Campaign for Education (GCE) national representatives in planning and presenting this event.
2. So far, five countries have successfully held their Global Action Week grand celebrations. These include Mali, Burkina Faso, Mozambique, Ghana, and Malawi, with complete reports having been specifically received from Mali and Burkina Faso.
3. In some countries like Burkina Faso, Malawi, Kenya, and Ghana, the national associations of the blind sit on boards and various committees of the GCE national representatives. This has improved the implementation of EFA-VI Campaign activities. This cooperation and integration most certainly has had a positive impact on GAW planning and implementation, since the GCE national representatives had to reach out to DPOs, including the national associations of the blind. Thanks to the 2014 GAW whose theme touched on disability, as well as to advocacy efforts put up by ICEVI and EFA-VI Campaign among other partners.

Objectives

1. Most national associations of the blind prepared briefs on the state of education of learners with visual impairment in their respective countries. The briefs included figures on enrolment, retention and transition rates, policy development and or implementation, teacher training, physical accessibility, etc. There were sound publications from Kenya, Ghana, Burkina Faso and Mali.
2. ICEVI ensured that the national associations of the blind followed the main objective of the GAW at the same time, raising the visibility of EFA-VI in the joint venture through their contributions.

ICEVI's contribution through associations of the blind

1. Active participation of national associations of the blind in periodic GAW planning meetings, as initiated by the GCE national representatives. Initially the meetings were twice a month but in the month of April they were held weekly. This is as observed in most Focus Countries.

2. Mobilising learners with visual impairment from school, colleges and universities.
 - ⌘ In Mali, for instance, a majority of learners were those with visual impairment, not surprisingly, since the function took place in the association's (I'UMAV) premises.
 - ⌘ During the celebrations in Burkina Faso, a majority of learners that attended were from ABPAM (the national association of the blind) school for the blind. ABPAM was the lead DPO in mobilising learners with disabilities.
 - ⌘ In Mozambique ACAMO (the national association of the blind) dominated mobilisation of participants. This year's grand celebrations in the country were conducted in the northern province of Nampula in partnership with Sightsavers, Light for the World, and other partners.
 - ⌘ In Kenya, the DPOs that mobilised participants were the Kenya Union of the Blind, the Kenya Society for the Blind, and the Kenya National Association of the Intellectually Handicapped.
3. Mobilising teachers and parents from the said institutions and communities respectively.
4. Giving reasonable financial contributions to the GAW in line with respective budgets. Direct contributions were made to GCE national representatives, and ICEVI's support was acknowledged. This year's EFA-VI budget had a line towards support of GAW. Focus Countries were awarded based on creativity and innovation in their plans for GAW.
5. EFA-VI Campaign in Mali was launched during the GAW celebrations.
6. The ICEVI Africa Regional Coordinator was present at the Mali and Burkina Faso grand celebrations. He strengthened existing relationships and made very useful new contacts.

Monitoring and reporting

- a. The Regional Coordinator got briefs from national associations of the blind and in some cases directly from GCE national representatives through minutes of meeting discussions.
- b. A full report with photos and footage will be made available.

ICEVI recommendations

1. We need to support and influence more countries with potential, like Tanzania, Lesotho, South Africa, and The Gambia, to formulate such education consortiums/GCE national representatives, since they have proved to be a good tool for advocacy and networking.
2. DPOs therefore must take advantage of the above tool to increase their level of advocacy in disability and education. This will most certainly impact positively on mainstreaming and inclusive development, minimising creation of separate and disability specific entities. After this GAW we should not sit down and wait for another GAW with a particular theme on disability. DPOs / INGOs MUST work with GCE and GCE national representatives for disability mainstreaming of every theme.
3. The GCE national representatives need to incorporate DPOs and other INGOs in disability and development work in their activities even beyond this year's GAW to enable the achievement of global Education for All, EFA.

EQUAL RIGHT

EQUAL OPPORTUNITY

Education and Disability

Global Action Week (2014)

- Kickoff event in INDIA

Bhushan Punani, Regional Chairperson, ICEVI West Asia Region

CBM's South Asia Regional Office (SARO) collaborated with the National Campaign for Education and other partners to establish a kickoff event for Global Action Week. In India, the Global Action Week was delayed because of elections in early May, and took place during the week of 19th – 25th May. Dignitaries began proceedings with a “lighting of the lamp”, and then hosted a series of prominent speakers from organisations such as UNESCO, the Global Campaign for Education, the Ministry of Social Justice and Empowerment, UNESCO, UNICEF India, the International Council for Education of Children with Visual Impairment (ICEVI), and other NGOs and INGOs. Among the speakers, there were five representatives from CBM.

Dr. Sara Varughese, Regional Director of SARO, shared a case study about a girl with multiple disabilities who was empowered to attend school with the use of Community Based Rehabilitation in her village. The story underlined the key point that it is of paramount importance to reach out to communities, schools, and parents to develop awareness and capacities regarding inclusive education. Dr. Varughese also cited another CBM project in Chamarajnagar, in which educators are being trained to think inclusively, as another necessary approach for promoting implementation of inclusive education.

Dr. M.N.G. Mani, CEO of the International Council for Education of People with Visual Impairment (and also a CBM advisor), spoke on the importance of getting children with disabilities enrolled in school and ensuring that they were receiving the same quality of education as their peers. He called for all teachers to receive additional training on inclusive and special education methodologies, and for the education system to be sensitised to the needs of all learners.

Other speakers from CBM partners include Dr. Anil Aneja, Vice President of All India Confederation of the Blind, and Mr. Parthiban, National Secretary from the Self Advocates Forum of India (SAFI), which was formed by Parivaar, a parents’ organisation supported by CBM. Mr. Umesh Baurai, Advocacy Manager of SARO, presented to the participants the Charter of Demands to be presented to the President of India. This Charter was drafted by the National Coalition for Education, using inputs of different civil society organisations in India. Comments were further invited on the draft charter.

As many schools were closed for summer during the Global Action Week in India, CBM SARO will follow up the event with organised activities and gatherings on the state level throughout India. The planning process is ongoing, and the additional events will take place throughout the rest of 2014.

Here and there

ICEVI Activities from January to June 2014

Participation in IDDC Task Group

ICEVI is now a member of the Inclusive Education Task Group (IETG) of the International Disability and Development Consortium (IDDC). In February 2014, Dr. M.N.G. Mani, ICEVI's CEO, attended the face-to-face meeting of IETG held at the CBM office in Brussels, Belgium. One of the key recommendations of the task group was to celebrate the Global Action Week (GAW) 2014, which lays a special focus on disability. Subsequently ICEVI encouraged its Regional Chairpersons to organise a number of programmes, including capacity building, lobbying with governments for strengthening proactive policies about disability etc. The Africa, Latin America, and West Asia regions collaborated with many of our international partners at the regional and national levels to organise activities to observe the Global Action Week.

Discussions on WBU-ICEVI Joint General Assemblies

As a result of the successful joint assemblies of WBU and ICEVI held in Bangkok in 2012, the ICEVI Executive Committee endorsed the proposal to organise joint assemblies in 2016. The USA's National Federation of the Blind (NFB) in Baltimore, Maryland, has made a bid to host the assembly. WBU's Arnt Holte (President) and Penny Hartin (CEO) joined ICEVI's M.N.G. Mani (CEO) in detailed discussions with the officers of NFB. They also visited a few potential venues in Baltimore. Final decision on the 2016 venue will be communicated soon through e-mail, publications and website. One of the features proposed in the joint assembly is that ICEVI will

have a day dedicated exclusively to academic presentations by professionals. More details of the format of the joint assembly will be available soon.

ICEVI's involvement in GCE

Since the WBU-ICEVI Joint World Assembly held in 2012, ICEVI has been collaborating with the mainstream initiatives on education. ICEVI has approached the Global Campaign for Education (GCE) for formal membership which will be taken up by the GCE in the future. ICEVI believes that it will be able to influence general initiatives to incorporate issues dealing with disability, making the general system more inclusive in nature.

ICEVI in CCNGO-EFA Meet

ICEVI was invited by the Collective Consortium of Non-Governmental Organisations (CCNGO) on Education For All to attend its meeting held in Chile on 21-23 May 2014. Lucia Piccione, 1st Vice-President, represented ICEVI at this important event and shared the experiences of the EFA-VI Global campaign.

ICEVI Technology Strategy

Technology plays an important role in implementing ICEVI's strategy. Colin Low, President of ICEVI, is heading an initiative to develop an appropriate strategy in technology that will be integrated into the EFA-VI Campaign. This has the potential to enhance the learning experiences of students with visual impairment, as well as expand educational opportunities for children who are currently un-reached in developing countries. We are working on a

proposal which will encourage our international players to actively support the technology initiative. Further development in this area will be announced to the ICEVI members in the second half of 2014.

Higher Education Coordinators Meet

The coordinators of the higher education programme supported by the Nippon Foundation met in Phnom Penh, Cambodia, in February 2014 to plan specific implementation strategies for the year 2014-15. The coordinators suggested that the fruits of higher education can be felt only when successful rehabilitation takes place in the case of visually impaired individuals. A core group met in Manila in March 2014 to identify additional recommendations for the higher education project, in support of increasing the employability of visually impaired individuals. The group resolved that the higher education programme implementation in the

future should include development of job skills in persons with visual impairment. This will include training in soft skills in addition to academic studies. These components will be built into the future activities of higher education (2015-16 onwards) in order to facilitate a smooth transmission of students with visual impairment from education to employment.

Promotion of Parents' Activities

ICEVI had a meeting with the officials of PAVIC (Parents Advocates for Visually Impaired Children) in Manila, the Philippines, on 22nd April 2014, to strengthen joint activities in the East Asia region. ICEVI works closely with the International Parents' Association for the Visually Impaired and it is in the process of promoting parents' association activities at the regional levels. ICEVI supported PAVIC in organising its 4th National Parents Congress in Manila from 9 to 11 May 2014.

Quotes about Parents

- I know God will not give me anything I can't handle. I just wish He didn't trust me so much.
- Mother Teresa
- You've developed the strength of a draft horse while holding onto the delicacy of a daffodil ... you are the mother, advocate and protector of a child with a disability.
- Lori Borgman
- There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.
- Albert Einstein
- Enjoy the little things, for one day you may look back and realize they were the big things.
- Robert Brault
- The only way we can be there for our children is to be there for ourselves.
- Anonymous
- Children remind us to treasure the smallest of gifts, even in the most difficult times
- Allen Klein
- Anyone can give up, it's the easiest thing in the world to do. But to hold it together when everyone else would understand if you fell apart, that's true strength.
- Christopher Reeves