

The Educator



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Reaching *the* Unreached



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People with Visual Impairment

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Our International Partners



Message from The President



Since we were last in contact, the IDP Africa Forum held in Kampala, Uganda in October 2015, postponed from the previous year on account of Ebola, provided an excellent focus for international collaboration. We were able to

showcase our Global Campaign on Education For All Children with Visual Impairment (EFA-VI), which was given a major boost by a video message of support from Gordon Brown, the former UK Prime Minister and now the UN Secretary-General's Special Envoy for Global Education. We nearly couldn't get it to play, but Dr Mani, with great presence of mind, came rushing up to the podium with his laptop and saved the day.

We were also able to hold a meeting of the Executive Committee. There was a lively discussion of the new Articles of Association, ICEVI's constitution, prepared by our lawyers, Bates, Wells and Braithwaite, leading charity lawyers in London. A number of changes were agreed and discussed with the lawyers, but we will need to take a little more time to resolve some issues thrown up by our desire to develop constitutions for our regions, and also to allay concerns raised by some of our international partners.

You will be glad to know that the EFA-VI Campaign, implemented in partnership with the World Blind Union (WBU), was selected as one of the 86 innovative practices by the Zero Project, Austria, and Larry, Mani and I attended its conference and the award ceremony held in Vienna in February. Many international organisations and individuals showed interest in ICEVI's work and we look forward to the EFA-VI Campaign gaining even greater traction with this increased exposure.

2016 will be an important year for ICEVI as we organise our second Joint General Assembly in collaboration with our WBU colleagues. The 2012 Assembly in Bangkok generated a lot of goodwill and camaraderie between WBU and ICEVI, and we are looking to progressively strengthen this collaboration at all levels. As an example, we were able to make the most of the Africa Forum in Kampala last October to bring WBU and ICEVI members together at the regional level to plan strategic activities to expand the EFA-VI Global Campaign in the region and also to strengthen joint work on advocacy.

As further instances of collaboration, the ICEVI West Asia region and the Asia Blind Union will be holding a Joint Regional Conference in Ahmedabad, India, this March, and the WBU and ICEVI members of the North America/Caribbean region are proposing to have a joint meeting in conjunction with the General Assembly in Orlando.

These joint activities are testimony to the stronger collaboration between the two organisations, which augurs well for joint action to improve educational opportunities for children with visual impairment.

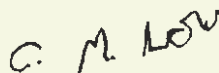
This issue of The Educator focuses on "Reaching the Un-reached" and has an excellent selection of articles written by authors representing the different regions of ICEVI. Dr. Marianne Riggio, the Editor from Perkins School for the Blind, has done a brilliant job in bringing together a range of articles which will serve as wonderful resources for training programmes and enabling researchers to know more about the status of education of visually impaired children in different parts of the world. An important development in the forthcoming Assembly compared with Bangkok will be the staging of an "ICEVI Day" as part of the Joint Assembly devoted to paper presentations along the lines of the traditional ICEVI conference.

The topics of the articles in this issue mesh well with the theme of this ICEVI Day “Education For All Children with Visual Impairment: Beyond 2015” and I am sure that many of the authors will be present. We are delighted that Mr. Sasakawa, Chairman of the Nippon Foundation and one of our major funders, and Mrs. Camilla Croso, Chairperson of the Global Campaign for Education, have each agreed to give a keynote address at the inaugural session of the ICEVI Day which will be held jointly with WBU.

Finally, in recognition of ICEVI’s developing role, particularly in the areas of networking and

advocacy, we are proposing to conduct a Strategic Review of the vision, mission and objectives of ICEVI at the beginning of the next Quadrennium.

In summary, 2015 has been a very productive year for ICEVI and we look forward to another constructive year for the organisation in 2016.



Colin Low
President, ICEVI

Message from The Editor



Dear colleagues and friends,
I am pleased to share with you the latest edition of the *Educator*, dedicated to the topic of Reaching the Unreached. It was amazing to receive an outpouring of responses to this theme.

I'm sure that you will enjoy the diverse articles that we received. As you read you will travel to all corners of the world, including remote areas of Australia; the Kibera slum in Nairobi and to the Philippines - so many different cultures and solutions to the challenges of getting to the millions of children and young adults in need of services. They are all a testimonial to individual commitment and creativity of people in our field.

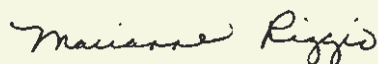
As we thought about the next issue of the *Educator*, we looked back and were surprised to find that fifteen years has passed since our last issue that was dedicated solely to topics in Early Intervention, so it seems like an important time

to address it again. It is a topic that is very timely since, in many countries creative models of early intervention are being developed to support the youngest members of society.

The theme will be Partnerships in Early Intervention since, at every level, it is a partnership. We are hoping to see articles that speak to partnerships with families; partnerships between medical and educational communities; partnerships between programs and governments. We are also hoping to see articles that relate to services for unique segments of the population, teacher training, and of course individual case studies.

In the meantime, I hope that you will be inspired as you read on.

With gratitude and best wishes,



Marianne Riggio
Editor

ICEVI ACTIVITIES

July - December 2015

2015 has been a very productive year for ICEVI. The EFA-VI campaign was expanded to many countries in the regions of ICEVI and the Higher education programme included the employment component in the next phase of implementation. Following are some of the highlights of ICEVI activities during the year.

- The enrolment of children with visual impairment in the participating EFA-VI countries has exceeded 105,000 with the support of all stakeholders. We are glad that the Zero Project Austria selected our Global Campaign for Education of Children with Visual Impairment (EFA-VI) as one of the most innovative approaches for inclusive education and ICEVI attended the Award Ceremony of the Zero Project held in Vienna on 10-12 February 2016.
- The EFA-VI Global Campaign was re-launched at the IDP Africa Forum held in Kampala, Uganda in October 2015. We could get a video message from Mr. Gordon Brown, Special Envoy of the United Nations for Global Education supporting the EFA-VI Global Campaign and this message was shared with the delegates of the IDP Africa Forum and also posted on ICEVI website.
- ICEVI regions organised activities in connection with the Global Action Week of the Global Campaign for Education (GCE). These programmes created greater awareness in the public about the potential of persons with disabilities.
- The ICEVI East Asia region organised its Regional Conference 2015 in Bali, Indonesia from 28th September to 1st

October 2015, which was attended by more than 250 delegates.



- The Nippon Foundation (TNF) is pleased with the progress of the Higher Education programme being implemented in countries in the East Asia region and extended financial assistance for the project cycle 2015-18. Mr. Suichi Ohno, Executive Director of the Nippon Foundation received a special award at the East Asia regional conference in recognition of the support of TNF to ICEVI. Mr. Sasakawa, Chairman, TNF and Colin Low, President, ICEVI had a meeting in London in November 2015 and discussed collaborative activities and future partnership. Mr. Sasakawa has also agreed to deliver the inaugural address at the ICEVI Day of the WBU-ICEVI Joint Assemblies.
- A meeting of the coordinators of higher education programmes was organised in September 2015 to fine tune activities for

implementation under the new project cycle 2015-18.

- The International Organising Committee of the ICEVI – WBU Joint Assemblies 2016 met in Orlando in November 2015 to finalise the programme for the General Assemblies. Abstract selection for the ICEVI Day presentations was over and the presenters have already been informed.
- ICEVI strengthened its collaboration with the SEAMEO (South East Asian Ministers of Education Organisation) during 2015 to influence policy changes to promote inclusive education for children with disabilities in the East Asia region.
- ICEVI has formed a strategic partnership with the DAISY Consortium to provide practical solutions for print disabled people. Colin Low, President, ICEVI and Richard Orme, CEO, DAISY are leading the technology initiative and made a visit to Mauritius to work on a pilot project.
- In continuation of the meeting of the Vision Alliance Team with Mr. Barry Palmer, President, Lions Clubs International in London in March 2015, the ICEVI regional chairs have been requested to prepare joint plans of action for implementation of education and rehabilitation activities in collaboration with the local Lions clubs.
- ICEVI made an oral statement at the UN-ECOSOC meeting in New York in July 2015. Kay Ferrell, our Regional Chairperson of North America and Caribbean region represented ICEVI at this event.

- A meeting of the Texas School for the Blind, Perkins School for the Blind and ICEVI was held at Austin, Texas in November 2015 to discuss a proposal to prepare Mathematical video packages based on ICEVI's publication "Mathematics Made Easy for Blind Children". A detailed concept paper has been prepared and shared with the International Partner Members of ICEVI for their support.
- Substantial discussions took place at the EXCO meeting of ICEVI to amend the present constitution of ICEVI, which will make ICEVI a strong networking organisation. A Board policy on Partnership has also been developed.

2016 is going to be special year for ICEVI as the 2nd Joint General Assemblies of the World Blind Union and the ICEVI will be held in Orlando in August 2016. We are also glad that the ICEVI will be undertaking a Strategic View of ICEVI at the beginning of the next Quadrennium to define its renewed Vision, Mission and Objectives. More information on the Strategic Review will be posted on the website of ICEVI and also published in the subsequent issues of The Educator.

Arman's Way to Home

Hasmik Dzvakeryan, Gyumri Children's Home, Armenia

This is a story about Arman, an Armenian boy with deafblindness who lived in an orphanage for a while, far from his family. In Armenia, parents of children with disabilities are still frequently pressured to bring their children to orphanages. Unfortunately, many children live in these institutions, without knowing what a parent's love really is. This is a fate that Arman escaped, thanks to teachers who learned how to reach children who are deafblind.

Arman was born in 2005, and for the first nine months of his life he lived with his family. His parents didn't know how to take care of him or deal with the problems associated with his deafblindness, which promised to intensify in the future. They made the decision to take Arman to an orphanage.

When Arman came to Gyumri Children's Home, he had behavioral problems. Although he was deafblind, he had some hearing, but was not using it effectively. He didn't have any means of communication, and sometimes he screamed and cried. We tried to communicate with Arman, but we lacked experience in working children like Arman.

We asked Perkins International for help, and the organisation arranged training and workshops for the staff of the Children's Home. From these trainings we gained some basic skills for working with children with deafblindness and visual impairment with additional disabilities. We were especially grateful that some of our specialists participated in the Educational Leadership

Programme (ELP) at Perkins School for the Blind.

Perkins' ELP training focuses on teaching special educators who work with students with deafblindness and MDVI. They benefit from direct experience working in the classrooms at the school. The Children's Home educators returned with new skills and knowledge for working with Arman.

The staff decided to invite Arman's family for Parents' Day, which was organised with the help of Perkins International. Arman's parents were living in Russia, but his grandmother and uncle came to visit him. He had become a rather independent child, with orientation and mobility skills, and he could communicate with some basic gestures.

Arman's grandmother was very excited, and shared her impression with his parents, who had not visited him for a long time. Eventually Arman's father returned to Armenia to visit him. It was very touching to see their reunion. When Arman hugged his father, he could not hold back his tears.

During the second Parents' Day the staff of Gyumri Children's Home was very happy and excited to learn that Arman's parents had decided to take him back home. He now lives in Russia with his parents and brothers.

The staff of Gyumri Children's Home is proud and happy that their training gave them the skills to reach Arman and help him to become as independent as possible. The reunion of Arman and his family is one of the Children Home's success stories.

Beyond Reading & Writing: Technology, Social, and Living Skills of a Select Group of Academically Capable Blind Students in the U.S.

Karen E. Wolffe, Career Counseling & Consultation, United States
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[NB: The authors would like to acknowledge the contributions of Sharon Z. Sacks, California School for the Blind, and Nancy Niebrugge, Braille Institute, to the reported research effort.]

Lifestyle studies with adolescents who have visual impairments have demonstrated that while many of the individuals queried reportedly are leading full lives, they may be at risk in the following areas: technology use (academic), social engagement, performance of activities of daily living, and vocational participation (Kelly & Wolffe, 2012; Shaw, Gold, & Simson, 2005; Wolffe & Sacks, 1997). Although adolescents with visual impairments in these studies tended to make grades comparable to their sighted peers, many spent considerable time by themselves engaged in passive activities, had smaller groups of friends, fewer opportunities to engage in work experiences, and experienced lower family expectations for completing independent living tasks when compared to their sighted age-mates (Gold, Shaw, & Wolffe, 2005; Kef, 1997; Newman, Wagner, Cameto, Knokey, & Shaver, 2010; Sacks, Wolffe, & Tierney, 1998). Over time student outcomes in the areas of social skills, activities of daily living (ADL), career and vocational skills, recreation and leisure skills, and academic skills have not increased or changed dramatically, even given curricular emphasis on the Expanded Core Curriculum (ECC) and the availability of specialized curricula for

teaching these skills (Gold, Shaw, & Wolffe, 2010; Shaw, Gold, & Wolffe, 2007; McDonnall, 2011; McDonnall & Crudden, 2009; Wolffe & Kelly, 2011).

In this article, the authors present the results of a lifestyles study completed in the United States, which focused on 20 students who were blind or severely vision impaired (VI) and used braille as their primary literacy medium. Their parents and teachers of students with VI were also surveyed, resulting a total respondent group of 60 individuals.

Research Questions

To investigate how these students perform in important areas of their lives, we asked the following research questions:

1. Is there agreement among students, their teachers of students with visual impairment, and the students' parents with respect to the students' use of technology (academic survey), level of social engagement (social survey), and performance in activities of daily living (ADL survey)? And, do these responses vary by student age group – younger (9 to 13 years old) versus older (15 to 19 years old)?

2. What do the students, their parents, and the students' teachers of students with visual impairments think they will be doing following high school (attending postsecondary training, university, working, etc.)? And, do these responses vary by student age group – younger (9 to 13 year olds) versus older (15 to 19 year olds)?

METHOD

Instrumentation

In order to test their hypotheses, the researchers designed five surveys based on previous research studies (Wolffe & Sacks, 1997; Gold, Shaw, & Wolffe, 2005; Shaw et al., 2005). The surveys focused on the following domains: Academics, including assistive technology; activities of daily living; social and recreational engagement; and vocational involvement. In addition, a survey was designed to capture demographic information. Parallel surveys were created for students, their parents or caregivers, and for the students' teachers of students with visual impairments (TVIs). The surveys were field tested, revised, and placed on Survey Monkey in accessible formats for respondents.

Procedure

Following Internal Review Boards approval, participants were recruited for the study. Initial contact with students and families was made during the 2012 Braille Challenge Finals in Los Angeles, California. Subsequent recruitment of Braille Challenge finalists and their families took place via email and telephone. The staff of the Braille Institute provided finalists' emails, after they received permission to do so from interested individuals and the primary investigators sent formal letters of invitation to participate in 2013.

After permissions were secured, students were contacted by the team's research assistant. She determined if students and families wanted to complete the surveys directly via Survey Monkey or via a telephone interview. Ninety per cent of the participants completed the surveys via Survey Monkey with no support from the research assistant. During the initial telephone contact, the students and parents were asked to provide contact information for the students' TVIs. A letter was sent to each TVI via email inviting them to participate in the investigation along with a permission form to complete.

Students, parents, and TVIs were instructed to complete and submit each survey on Survey Monkey, unless they indicated that they would prefer to complete their surveys via telephone interview. The principal investigators monitored survey submissions, and followed up with participants via email and telephone when the surveys were not completed in a timely manner. Each triad (student, parent, and TVI) who completed all of the surveys received a gift card as a token of appreciation.

Data Analysis

Data from the surveys were analyzed using descriptive statistics as well as by individual groups and triangulated to compare findings. The standard alpha level of .05 ($\alpha = .05$) was used to assess if there was a significant difference or not. We used the Mann-Whitney U test (Wilcoxon, 1945) to compare differences between our two independent groups (younger and older students). We had two equal groups of students (ten per group) and the younger students were 9 to 13 years old, the older students were 15 to 19 years old. Differences among the three groups of survey respondents (students, parents, and

teachers) were further analyzed using the Kruskal-Wallis test (Kruskal & Wallis, 1952) for each of our research questions that yielded significant results. The results of our analyses follow.

RESULTS

Demographic Information

Twenty students with visual impairments, one of their parents, and their TVIs (for a total of 60 respondents) participated in the study.

Students ranged in age from 9 to 19 years of age, in grades three through freshman year in college. All of the students were educated in inclusive school programs. Two of the student participants had mild disabilities in addition to their visual impairments. Seventy percent of the students were functionally blind and 58% were female. Half of the students were younger (grades 3-7) and half older (grades 9 up). Table 1 provides detailed information about the students and their families.

Table 1
Demographic Characteristics of Students

	Number	Percentage
All	20	100%
Gender		
Male	9	42%
Female	11	58%
Grade		
3	1	5%
4	0	0%
5	5	25%
6	2	10%
7	2	10%
8	0	0%
9	1	5%
10	5	25%
11	1	5%
12	1	5%
College freshman	2	10%
Braille media use		
Students who read braille	20	100%
Students with parent who reads braille	9	45%
Visual status		
Blind	14	70%
Some useable vision	6	30%
Onset of Visual Impairment		
Congenital	16	80%
Adventitious	4	20%
Type of Community		
City	6	30%
Suburb	9	45%
Small town/village	2	10%
Rural	3	15%

RESEARCH QUESTION ONE RESULTS

Technology (academic survey)

Agreement among students, their teachers, and their parents. We found no significant differences with the youth's degree of technology use (that is, use of Internet and email for school-related tasks) when comparing the responses of students, their teachers, and their parents to this survey item. However, we did find significant differences when considering the age groups of the students.

Agreement among younger and older students. We investigated which age group can be considered as having reported more use of Internet and email for school related tasks. In this case, the older age group (15-19 years

of age) had significantly more reports of Internet and email use for school-related tasks than the younger age group (9-13 years of age).

Descriptive Results. Students, parents, and teachers agreed that most students were comfortable or very comfortable with Assistive Technology (85-95%). Approximately half of the students were considered comfortable with mainstream technology; however, almost a third were uncomfortable. Internet and email use was significantly different between the younger and older age groups. The latter group used both more than the former. Student, parent, and teacher responses were similar. Most students used the Internet for completing school-related tasks; and email to a slightly lesser extent. Details are contained in Table 2.

Table 2
Responses to Technology Items (Academic Surveys)

	Respondents					
	Students		Parents		Teachers	
	%	n	%	n	%	n
Student Uses Internet for School Tasks						
Yes	89	16	89	17	95	19
No	11	2	11	2	5	1
Total respondents	100	18	100	19	100	20
Student Uses E-mail for School Tasks						
Yes	76	13	74	14	65	13
No	24	4	26	5	35	7
Total respondents	100	17	100	19	100	20
Student's Comfort Level with Assistive Technology						
Not comfortable	0	0	5	1	5	1
Somewhat comfortable	5	1	0	0	5	1
Comfortable	25	5	28	5	30	6
Very comfortable	70	14	67	12	60	12
Total respondents	100	20	100	19	100	20
Student's Comfort Level with Mainstream Technology						
Not comfortable	24	4	26	5	30	6
Somewhat comfortable	29	5	0	0	20	4
Comfortable	24	4	42	8	15	3
Very comfortable	24	4	32	6	35	7
Total respondents	100	17	100	19	100	20

Social Engagement (social survey)

Agreement among students, their teachers, and their parents. Respondents almost universally felt that these students got along well with other students the same age and that they were liked by other students. This was the case among students of all ages, their teachers, and their parents. There were no significant differences in the measures of social engagement across groups of any kind. For example, there were no significant differences among groups in terms of the number of close friends the students had acquired. Friendship was investigated in terms of overall friends, sighted friends, friends who are visually impaired, and best friends without finding any significant differences among any of the groups.

Descriptive Results. Although there were no statistically significant results regarding social engagement, there were interesting descriptive results and Table 3 provides details about these results. For instance, all of the students felt that others wanted to befriend them, while 85% of parents and 70% of teachers agreed. According to all respondents, the majority of these students had friends, both sighted and visually impaired. However nearly 80% of

students and parents felt that students had best friends, yet only 50% of the teachers thought so. Likewise, students (95%) and parents (100%) felt the students' friends understood visual impairment, but only 75% of the teachers agreed.

Of concern to the authors, 47% of students and 33% of parents felt students had been bullied, while only 25% of teachers thought so. Students (75%) and teachers (74%) felt that the students' visual impairments did not inhibit their activities; however, parents were not so sure as only 56% indicated that their child's visual impairment did not inhibit activities.

Virtually none of these students had dated and only one indicated that he or she had a boy/girlfriend. Most of the students (85%), parents (100%), and teachers (75%) indicated that students spent their time out of school with parents. Fifty percent of students indicated that they spent time with friends and 49% said they spent time alone and these percentages were mirrored in the teachers' and parents' responses. Respondents were able to choose more than one response to this item concerning how students spent their time out of school.

Table 3
Responses to Social Engagement Items (Social Surveys)

	Respondents					
	Students		Parents		Teachers	
	%	n	%	n	%	n
Number of close friends students has						
No close friend	5	1	5	1	5	1
One close friend	5	1	11	2	30	6
Two close friends	20	4	21	4	10	2
Three close friends	20	4	11	2	15	3
Four close friends	25	5	16	3	10	2
Five close friends	0	0	11	2	5	1
More than five	25	5	26	5	25	5
Respondents	100	20	100	19	100	20

Student gets along with others the same age						
Yes	95	19	95	19	100	20
No	5	1	5	1	0	0
Total	100	20	100	20	100	20
Others like student						
Yes	100	19	95	19	100	20
No	0	0	5	1	0	0
Total	100	19	100	20	100	20
Others want to be friend						
Yes	100	20	85	17	70	14
No	0	0	15	3	30	6
Total	100	20	100	20	100	20
Student has a best friend						
Yes	80	16	79	15	50	10
No	20	4	21	4	50	10
Total	100	20	100	19	100	20
Student has dated						
Yes	0	0	0	0	5	1
No	100	19	100	19	95	19
Total	100	19	100	19	100	20
Student feel visual impairment inhibits activities						
Yes	25	5	44	8	26	5
No	75	15	56	10	74	14
Total	100	20	100	18	100	19
Student has been bullied						
Yes	47	9	33	6	25	5
No	53	10	67	12	75	15
Total	100	19	100	18	100	20

Activities of Daily Living (ADL survey)

Agreement among students, their teachers, and their parents. Across the wide range of activities of daily living that were measured by the survey instrument (e.g., shop for or help with groceries, use the microwave, help with laundry, take care of personal hygiene, vacuum, wash the car, take out the trash, help with yardwork, etc.), there were no significant differences in the responses of students, teachers, and parents.

Agreement among younger and older students. Older students appeared to be more confident than younger students when

performing ADL skills and projected a slightly higher degree of confidence they would live independently; yet, only two items (choosing clothes and using the stovetop) were statistically different between the older and younger groups. In both instances, students in the older age group reported a significantly higher degree of independence than the younger age group. That is, the older age group reported significantly more confidence choosing their own clothes and using the stovetop than the younger age group.

Descriptive Results. According to students and parents, the students' best skills were:

Personal hygiene, use of microwave, choosing their own clothes, helping with grocery shopping, preparing snacks, and picking up the mail. Their moderate skills included: Vacuuming, dusting, washing/drying dishes, preparing meals, using oven/stovetop, and taking out the trash. Their weakest skills were: Banking skills (checking, savings, credit/debit); helping with laundry; washing the car; and yard work. When asked if they contributed at home, most students (79%) responded positively; 95% of their parents agreed as did 79% of their teachers. When asked if they would live independently, most students (78%) thought so; 95% of parents and 63% of teachers agreed. Asked if they would need help to live independently, 37% of students said yes; 42% of parents and 37% of teachers agreed.

RESEARCH QUESTION TWO RESULTS

Post High School Engagement in School and Work

To address the second research question, we first looked for significant differences in the perceptions of the respondents concerning whether students would attend a college or university following high school and second whether they would have jobs following high school. We also investigated whether there were significant differences in the responses for younger (9-13 year olds) versus older (15-19 year olds) students for the same queries.

Significant differences in agreement among students, their teachers, and their parents with post high school engagement in work.

The only significant difference that we found in our analysis of the second research question was among the students, their teachers, and their parents in terms of whether or not they

felt the young person would get a job post high school or not get a job post high school. The results showed that the students most often reported plans for post high school engagement in work followed by the parents and then the teachers. There was a significant difference between the following groups, as described below.

Students vs. teachers: The results of these analyses revealed a significant difference between the students' and teachers' perception of the students getting a job post high school. From this data, it can be concluded that the students were significantly more likely to report that they thought they would get a job post high school than the teachers.

Parents vs. teachers: The results of these analyses revealed a significant difference between the parents' and teachers' perceptions of the students getting a job post high school. From this data, it can be concluded that the parents were significantly more likely to report the students would get a job post high school than the teachers.

There was no significant difference between the following groups: students vs. parents. The results of these analyses revealed no significant difference between the students' and parents' perceptions of the students getting a job post high school. From this data, it can be concluded that the students were not significantly more likely to report the students would get a job post high school than the parents.

Descriptive Results. According to all of the respondents, these students were expected to attend college or university following high school. However, only students (74%)

consistently identified job outcomes in their futures. Fifty-five percent of parents also identified job outcomes in the students' futures, but only 21% of teachers did so. A similar pattern was in evidence concerning whether the respondents foresaw marriage in the students' futures: 53% of students thought

they would marry, 44% of parents agreed, but only 16% of teachers agreed. All of these details concerning postsecondary outcomes are reported in Table 4. It is important to note that the respondents could choose more than one outcome in response to this query.

Table 4
Responses to Post High School Engagement Items (Academic Surveys)

	Respondents*					
	Students		Parents		Teachers	
	%	n	%	n	%	n
Postsecondary outcomes						
Two year college	5	1	5	1	5	1
Four year college	95	19	94	17	84	16
Vocational Training	5	1	0	0	11	2
Job	74	15	55	10	21	4
Marriage	53	11	44	8	16	3
Undecided	11	2	11	2	21	4

*Note. The number and percentage of respondents varies within these results as a result of this survey item not having mutually exclusive response options (i.e., respondents could select more than one response option).

DISCUSSION

This study allowed us to examine the lifestyles of students who were academically capable students as evidenced by their participation as finalists in the National Braille Challenge and their strong grade reports in school. While previous lifestyle studies focused on an adolescent population of students who were blind and low vision with varied academic abilities, this study provided us with the opportunity to examine a more homogeneous group of students who were excellent braille users and academically successful. Using five survey questionnaires (demographics, academic, independent living skills, social, and vocational), and triangulating the data from students, parents, and teachers of students with visual impairments interesting findings were yielded in all aspects of the investigation.

The data confirm that these students were proficient with assistive technology, and expected to further their education post-high school in higher education programs. In addition to the students being skilled with braille, the demographic characteristics of the participant showed that almost half of their parents reported that they knew braille, which may be a contributing factor to their children's academic success.

There was a significant difference in the respondents' perceptions of post-high school engagement related to work. Far more students and parents thought the young people in this study would move into work than did their teachers. The descriptive statistics clarify that the majority of students strongly believed they would move into jobs. All respondents agreed

that the students would pursue postsecondary studies, but without the linkage to work that effort may be less than adequate to ensure successful employment outcomes. Teachers, in particular, and parents may want to spend more time discussing the future and relating postsecondary training to employment opportunities with youngsters.

Although there were not many appreciable differences between the older and younger students, the older students appeared to be more confident than younger students when performing ADL skills and projected a slightly higher degree of confidence they would live independently – these differences were statistically significant only in that the older age group reported more confidence choosing their own clothes and using the stovetop than the younger age group. These age-related differences were also apparent in that the older age group of students had significantly more reports of Internet and email use for school related tasks than the younger age group did. Finally, there was consensus between the respondents that these students were less confident in the use of mainstream technology than they were with assistive technology and that is a finding that could impact the students' ability to move successfully into adult life.

Study Limitations

This was a convenience sample of students who volunteered from the National Braille Challenge finals, their parents, and their teachers. Despite attempts by the researchers to collect data in a systematic and structured manner, participants' responses were by self-report and based on their perceived views. The use of Survey Monkey or telephone interviews allowed for questions to be similar across all

three groups, but an individual's knowledge or firsthand view of a student's skill level was of necessity based on perception rather than fact.

Another limitation is that while the data were triangulated across three separate groups, the sample size was relatively small. With only sixty respondents responding to questions concerning twenty young people, generalization of findings is limited. It will be important to repeat this study with additional groups of students to compare and contrast outcomes. However, it is important to note that despite the limitations addressed in this study, previous research studies have yielded a number of similar outcomes.

Implications for Practice

Although there are limitations with the present study, its findings provide some food for thought for practitioners concerning students with visual impairments who are academically successful yet may require additional support.

While students are introduced to an array of assistive technology devices, they also need to be familiarized with mainstream technology that will allow them greater access to academic and work-related activities.

Teachers may want to spend more time discussing student expectations for life beyond high school, both with individual students and their families: what jobs do they want to pursue, how will their postsecondary goals further their career aspirations, and do they have the skills they will need to make themselves marketable.

Implications for Further Research

The findings presented in this study provide a solid foundation for further research. This study captured insights into the lives of

academically successful students who are blind. However, more in-depth analysis is needed to clearly understand the findings from each set of surveys: academic, activities of daily living, social, and vocational; and to determine whether the results reflect successful engagement across the domains. It will also be important to expand the participant pool and replicate this study with additional students, their parents, and their

TVIs. In subsequent studies, it might be interesting to compare and contrast outcomes across different groups of students with visual impairments. For example, it might be interesting to determine if responses from students who participate in sports camps or an intensive Science Technology Engineering and Math (STEM) program are different or similar to responses from the Braille Challenge finalists who were our respondents.

ICEVI's International Network



GCE



GPE



IDDC



IDPP



SEAMEO SEN



UNESCO



UNICEF



World Blind Union

Stakeholders of the EFA-VI Global Campaign



Seeking Out the Unreached in Burkina Faso

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Preamble

Although Burkina Faso is one of the world's poorest nations, its school for the blind is an example to the world. The Burkinabe are committed to improving the quality of education and enrolling ALL children in school. The Ecole des Jeunes Aveugles (EJA) is a resource centre and a true centre of expertise. The enrolment rate has increased sharply over the past decade.

The initiative to embrace inclusive education came from the Disabled Persons Organisation for the Blind itself. Its members strongly believe that inclusive education is a vehicle for social inclusion, taking to heart the old African proverb, "It takes a village to raise a child." Students who are visually impaired attend the Ecole des Jeunes Aveugles for three years only, gaining the skills that will allow them to succeed in their neighborhood schools. Instead of institutional dormitories or hostels, these students are hosted by families who live near the school, and their well-being is monitored by social workers.

The success of inclusive education for Burkinabe students with visual impairments is supported by the collective efforts of the National Union of Associations for the Promotion and Protection of Persons with Visual Disabilities, the National Ministry of Education, Catholic Development Organisations, Light for the World, CBM, and other partner NGOs in Burkina Faso. Our wish

is that the story of inclusive education will inspire other schools to take up an inclusive approach to reaching all learners who are blind and visually impaired.

General information about Burkina Faso

Burkina Faso is a small West African country with a population of approximately 18,900,000. Although we are one of the poorest countries globally, we are filled with hope and high aspirations since the democratic elections of 2015. Almost half of Burkina Faso's population is under the age of 14. Nearly 70% live in rural areas, where access to basic services is scanty (U.S. Central Intelligence Agency, 2016).

The situation of children who are blind and partially sighted

In 2015, the Ministry of Social Action and Solidarity reported that there are 79,617 children (48,126 boys and 31,491 girls) with disabilities in the country, of which 82% live in rural areas. Reaching children with disabilities in the rural areas is therefore an essential part of any education programme. Of children with disabilities in school, 43% are at primary level and only 7.1% at secondary level, indicating that transitioning to secondary school is challenging. The gross enrolment rate of children with disabilities of 53.1% is dismal in comparison to the 2013 national primary school enrolment rate of 83.1%. (Burkina Faso Ministry of Social Action and Solidarity, 2015).

There are 8,850 children with blindness or visual impairment in the census of the Ministry of Social Action and Solidarity. Some of the leading causes of visual impairments include cataract, trachoma, xerophthalmia, glaucoma, and refractive errors.

Political environment

Burkina Faso has taken bold steps to include persons with disabilities, starting in 2009 with the ratification of the UN Convention on the Rights of People with Disabilities (plus optional protocol). This was followed by the adoption of the National Assembly Law on the Protection and Promotion of the Rights of Disabled People in 2010, which guarantees the right to inclusive education.

Inclusive education framework

The Ministry of Education developed an inclusive education policy, and in 2015 presented a strategy and a three-year implementation plan. The strategy was developed in consultation with all state and NGO stakeholders.

A national directorate on inclusive education for learners with disabilities was established in 2013. Its highly motivated team of 32 embarked on an awareness campaign within the education ministry at all levels. The staff have developed four manuals and teachers' guides on the topics of inclusive education, low vision, inclusive sport, and intellectual disabilities. Their tenacity and dedication have won the respect and support of colleagues within the education system.

UN-ABPAM's Partnership Approach

The National Union of Associations for the Promotion and Protection of Persons with Visual Disabilities (UN-ABPAM) has been

advocating for the educational rights of blind and partially sighted learners since 1987. Its flagship school, Ecole des Jeunes Aveugles (EJA), is in the capital city of Ouagadougou. The Burkina Faso Ministry of National Education considers it a model for educational services for students who are blind or visually impaired, and employs its 19 teachers. They teach learners attending the school as well as those who are educated in inclusive classrooms in surrounding regular schools.

At Ecole des Jeunes Aveugles, blind learners receive at least three years of specialised education to build up their cognitive, physical, social-emotional, and learning skills. During their first year at EJA, students are assessed for their strengths, interests, and weaknesses. They receive intensive training in basic concepts, numeracy, and braille literacy to prepare them for inclusion in a regular school. There are ten regular primary schools and fourteen regular secondary schools in Ouagadougou that include blind children. Of the 166 learners supported by EJA, 77 are in regular secondary schools, seven in regular primary schools, and 17 at University.

The school recently opened a kindergarten class. The teachers at EJA are coached and monitored by a special unit. The school has developed into an important resource and teacher training centre for the education providers. Blind student teachers also do their practical training there and serve as role-models to the pupils at the school. When they have qualified, the student teachers go home to their villages to teach.

Expanding to Serve Rural Children

Due to persistent traditional beliefs and prejudices, many children with disabilities

remain hidden in their homes and never attend school. In order to reach such children who are blind, EJA needed to decentralise and expand its activities. The school partnered with Catholic Development Organisations (OCADES), which administers schools and community-based rehabilitation programmes. CBR agents are trained to visit villages, raising awareness on disability and convincing parents to come forward with their disabled children. When agents identify children with visual impairments, they make sure they get any necessary medical intervention. This is followed by rehabilitation services, such as orientation and mobility training, to prepare them for enrolling in school. The collaboration between EJA and OCADES ensures the social and educational monitoring of the children.

Ecole des Jeunes Aveugles also created a partnership with Catholic Education in 2009. This decentralisation pilot serves the six towns of Tenkodogo, Ouahigouya, Gaoua, Pô, Koudougou and Kaya, all in the outlying areas of Burkina Faso. The goal is to include children with visual impairments in the local Catholic schools, which have UN-ABPAM specialised education units. The units accommodate many over-aged blind learners who were discovered by CBR agents and members of UN-ABPAM. The learners are equipped with the necessary skills in the specialised classes, and those who are able are eventually included in the regular classes. The development of this inclusive education pilot is being closely monitored by the Ministry of National Education.

Although Burkina Faso is on a good path, there is still a long way to go. We need to advocate more effectively for students with disabilities, and dedicate more human and

financial resources in order to reach the goal of education for all. There are still some critical challenges to overcome. We need to improve our early intervention services, and continue developing the skills of CBR agents. Eye health and visual screening need to be part of every school's health promotion programmes. Further training of teachers and management personnel is needed to ensure that we are serving our learners with disabilities throughout their educational careers.

Blind and partially sighted learners in Burkina Faso have very limited access to published material and textbooks in accessible formats. Despite the great interest in technology, it is rarely used to improve access to information. This book famine has an adverse impact on education outcomes, employability, and participation in society.

Plans for the future

Inspired by the presentations at the 2015 Africa Forum held in Uganda, UN-ABPAM, Light for the World, and the Ministry of National Education are collaborating with the Daisy Consortium to address the book famine. In the coming months, the DAISY Consortium will conduct seminars on accessible publishing and access technologies. We look forward to the Consortium's scoping visit, which would form the basis for a comprehensive strategy.

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Early Childhood Education for Children with Visual Impairment in Nepal

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The Need for Education for Visually Impaired Children in Nepal

Although education for children with disability in Nepal began in 1964, most children with visual impairment are still out of school. According to the latest data from the Department of Education, about 5,000 children with visual impairments are enrolled in schools. Considering that there are 30,240 children who are blind, and more than 90,000 with low vision in Nepal, this is a very small percentage.

A study of over 700 children with blindness enrolled in schools (integrated, inclusive and special) found that they were either born blind (67.3%) or acquired blindness during the first year of their lives (26.1%). These children need to be habilitated from an early age. However, because of lack of policy, school enrolment in Nepal began only after 6 years of age. In contrast, sighted children were being admitted from the age of 3 or 4 years. This has a significant impact upon children with visual impairment, creating devastating delays in development. This, in turn, affects their families, and society in general.

To address this problem, the Department of Education in 2007 established a National Task Force on Education For All Children with Visual

Impairment (EFA-VI - NTF). ICEVI Nepal joined with BP Eye Foundation, Nepal Association for the Welfare of the Blind, Nepal Association of the Blind, and CBR National Network to make this happen. The main objective of the task force is to ensure equal access to education for all vision impaired children, regardless of their age, sex, race, and geographic location.

Establishing Early Childhood Education for Children with VI

Nepal's Ministry of Education has been running Early Childhood Development Centers (ECDC) for children between 3-8 years of age since 2001. The goal was to increase enrolment and retention of children in primary schools. The initiative was successful, leading to a remarkable increase in primary school enrolment, for which Nepal was recognised by the United Nations. However, of the 34,000 ECDC's in the country, none of them had children with blindness and visual impairment (CWBVI) until 2013. This was a serious challenge to the rights of these children. This lack of access to early childhood services perhaps explains the low enrolment (<15%) of CWBVI in primary schools, compared to 94.5% enrolment for their sighted peers.

Regular schools have been reluctant to admit CWBVI, even when they're older than grade

level. Early Childhood Development Centers have been even more reluctant to accommodate preschool aged children with visual impairments. The staff fears having to take additional care for young children, believing that they're unable to care for themselves or participate in class activities unassisted. They are also concerned about increased costs. This enrolment disparity was discussed several times at EFA-VI - NTF meetings. However, in the absence of evidence supporting success for these students, the Department of Education was disinclined to initiate admission of CWBVI in Early Childhood Development Centers.

BP Eye Foundation: Breaking the barrier

BP Eye Foundation (BPEF), with long experience in blindness prevention and rehabilitation, took on the challenge of remedying this situation. The agency's eye care personnel (ophthalmologists and optometrists) trained at its first flagship project, BP Koirala Lions Center for Ophthalmic Studies. This NGO has played a crucial role in expansion of eye care services in Nepal in a short period of time. Its extensive outreach work revealed that children, particularly those with neuro-sensory disability, were the most marginalised. This led to the establishment of its second major project, the Children's Hospital for Eye Ear and Rehabilitation Services (CHEERS). CHEERS is a unique blend: a healthcare-providing institution, a pre-primary school, and a rehabilitation center, all under one roof. An earlier survey of stakeholders had revealed the main barriers to enrolment in ECDCs for children with visual impairments:

- The reluctance of parents to send their children to school;

- A lack of confidence and self-esteem among children with blindness or visual impairment;
- The unwillingness of school teachers and management to accept young CWBVI;
- A lack of human and material resources in the schools.

Compounding these issues was the absence of a government policy to support the enrolment of CWBVI in preschools. BP Eye Foundation's strategy was to address and overcome each of these barriers by designing a structured curriculum to address them specifically.

Objectives of Educating Children with Blindness and Visual Impairment

The CHEERS preparatory training programme for CWBVI started with four major objectives:

1. To prepare CWBVI for early enrolment at ECDCs;
2. To prepare an enabling environment for children at ECDCs;
3. To sensitise concerned stakeholders on the importance of early education for CWBVI;
4. Advocate with government to develop an enrolment policy for CWBVI in pre-primary schools all over the country.

Activities and Achievements

The initial challenge was to find eligible CWBVI between 3 and 8 years of age. Because of the stigma attached to blindness, Nepalese families had long hidden visually impaired children at home. BPEF created the Search Army, an innovative approach that created a wide network of health institutions, educational institutions, community-based organisations, and interested individuals. The Search Army surveyed rural communities to locate eligible children for enrolment at the

CHEERS. Other sources of child referral were ECDCs, eye hospitals, and primary eye care centers. They were sensitised on identification and the importance of early educational intervention for CWBVI.

When eligible children were located, some were keen to go to school. However, a large proportion of them had lost their self confidence and self esteem due to neglect and even abuse. To overcome this, our field workers developed an approach called Dream Planning. Field workers would meet with children at their homes, and tell stories of similar CWBVI who had become successful. The workers then asked these children what they would like to become, and wove stories in which the CWBVI is the hero. This would spark the child's enthusiasm for school.

The next barrier was parents' reluctance to send their children to school. The reluctance stemmed from many things: belief that the child was too young, doubt that the child could study or learn, financial hardship, inability to accompany the child, and the belief that the child would not be able to apply the education and knowledge in future life. Field workers addressed parents' fears through personal interaction, fee waivers, and hostel accommodations.

The final barrier was the schools' reluctance to accept such young CWBVI, as they had never done it before. To overcome this barrier, we collaborated with Department of Education staff to persuade ECDCs to accept the children on a pilot basis. We trained teachers and helpers at schools, provided resource materials, and created a support system. Teachers from the CHEERS Enabling Center visited the schools to encourage and support

the ECDC staff. A programme steering committee monitored all the activities, with involvement of members from different sectors including the Department of Education, the Ministry of Health, NGOs and INGOs.

A pilot project was started with 6 children at CHEERS. The average stay for a child at the Enabling Center was six months. Periodic evaluations were done both internally and externally using a set of tools developed specially for the programme, evaluating both major outcomes and the processes involved. Perceptions of mothers, care givers and facilitators were monitored periodically through interviews and focus group discussions.

The teaching staff used a structured curriculum to train the children. Alterations to the curriculum are made based on individual performance and potential. This flexibility is important because we encountered children who had deafness, autism and speech disorders in addition to visual impairment. Subsequently we made arrangements to train children with deafblindness as well.

Conclusion

This pilot project initiated in Nepal has been successful in enrolling young children with blindness and visual impairment in pre-primary schools, a right denied to them earlier. A systematic survey identified barriers, and BPEF staff addressed them. We have made progress in ensuring equal rights to young CWBVI. A significant outcome of this innovation is the change in attitude of parents, teachers, and school managers. Above all, our efforts brought a change in government policy, resulting in signing of a Memorandum of Understanding between BP Eye Foundation and Department of Education. BP Eye

Foundation served as the Resource Center for training government teachers. This programme has been a landmark development for early education of CWBVI in Nepal. We have facilitated their enrolment in ECDCs, and their progress through the national education system. The Ministry of Education continues to

provide the salaries of the facilitators as well as stipends and learning materials to CWBVI.

The CHEERS programme's success encouraged other parents, teachers, and policy makers, and more children have been referred to the Enabling Center.



CWBVI learning about different shapes and textures of objects



Mothers of CWBVI being trained in mobility skills

So far 67 children with disability have been enrolled to the Enabling Center. Most (70%) of them were boys and had blindness (53%) as

their disability (Table1). Among them 49 have graduated from the center and enrolled in pre-schools (Table 2).

Table 1:
Details of Children with Disability Enrolled at CHEERS from 16 January 2013 to 31 December 2015

S. No.	Children with Disabilities	Total Number	Boys	Girls
1	Blind	36	26	10
2	Deaf/Blind	3	1	2
3	Blind/Neuro	2	2	0
4	Low vision	7	4	3
5	Low vision/Autism	2	1	1
6	Blind/Autism	6	5	1
7	MR/Blind	1	0	1
8	Deaf	5	5	0
9	Blind/Autism/Dumb	3	2	1
10	Deaf/Neuro	2	1	1
	Total	67	47	20

Table 2:
Details of Children with Disability Enrolled at ECDC's / Resource room from 16 January 2013 to 31 December 2015

S. No.	Children with Disabilities	Total Number	Boys	Girls
1	Blind	33	24	9
2	Deaf/Blind	1	1	0
3	Blind/Neuro	1	0	1
4	Low vision	7	4	3
5	Low vision/Autism	2	1	1
6	Blind/Autism	2	1	1
7	MR/Blind	0	0	0
8	Deaf	3	3	0
9	Blind/Autism/Dumb	0	0	0
10	Deaf/Neuro	0	0	0
	Total	49	34	15

Feeling van Gogh: Making Art Accessible to Blind and Partially Sighted People

Ann Blokland, Curator of Education, Van Gogh Museum, Amsterdam, The Netherlands

"Maybe this is a silly question, but why should a blind person want to visit a museum?" A member of our museum staff asked this when we of the Education & Interpretation Department presented our plans for a programme for blind and partially sighted visitors. It's an understandable question, as art is first and foremost a visual experience. This is certainly true with Vincent van Gogh's paintings; their bold colours and vibrant brushstrokes have a direct impact on the beholder.

The answer to the staff member's question lies in understanding that people who are blind or partially sighted are just like sighted people. They like shopping or reading, going out for dinner, visiting a football match, a theatre or a museum. The loss of sight doesn't mean they don't want to do those things anymore and it is the responsibility of society to make it possible for them.

Museum for All

Vincent van Gogh's ambition to give expression to human existence resulted in beautiful, powerful paintings. His impressive life story can be read in his many letters, in which he describes his love of painting, as well as his disappointments and his struggle with mental illness. Van Gogh is world famous and the Van Gogh Museum attracts around 1.6 million visitors a year, from as many as 40 nations. They have the experience of a lifetime, judging by entries in our guestbook: "*Very beautiful*

and inspiring composition of pictures made by a really genius artist!" "Our visit was a dream come true." We want to make an inspiring and memorable museum experience accessible to everyone.

The Van Gogh Museum has recently made Corporate Social Responsibility part of its strategic policy. This means that we want to add value on a social level: offer an inclusive museum experience and create opportunities for people in difficult or vulnerable positions.

In the past we have taken people with visual disabilities into account. However, our results in creating an accessible building and accessible information (e.g., large print textbooks) were very modest. Considering our mission to make Vincent van Gogh's art accessible to as many people as possible, to enrich and inspire them, as well as our social responsibility as a museum, we felt a great urgency to make a bigger effort. With our creation of *Feeling van Gogh*, a content-driven programme for the blind and partially sighted, we have taken a first step in the direction of becoming a museum for all, including people with a disability.

Our goals for *Feeling van Gogh* were:

- To increase the accessibility of the life and work of Vincent van Gogh to visually impaired visitors and facilitate the enjoyment of the arts;

- To reach a new audience: to connect to a group that isn't familiar with art, and paintings especially, because of their impairment;
- To enhance the social role of the Van Gogh Museum by actively approaching the blind and partially sighted, cooperating, and giving them a positive boost through the art experience.

Reaching Your Audience

Even though The Netherlands ratified the UN Convention on the Rights of Persons with Disabilities, it is not yet implemented in Dutch laws or regulations. We expect the government to begin to do so in 2016. Programmes for the blind and partially sighted in Dutch museums are few, in comparison to countries like the United States and the United Kingdom, where legislation has urged museums to take action. So, with no real Dutch programme models to follow, we first we needed to get to know our target audience and learn from them.

Some statistics (Stichting Bartimeus Sonneheerdt, 2014):

- Around 350,000 people in the Netherlands are blind or partially sighted. This number will rise to around 380,000 in 2020, partly as a result of aging but also of diabetes affecting young people.
- 85% of all people with a visual impairment are 50 years of age or older. Of these, about two-thirds are women.
- Between 2500 and 3000 children and youngsters with visual impairments are in school, of which 75% go to an "ordinary" school.
- Approximately 35% of the blind and partially sighted persons in the Netherlands have a job, compared to 67% of the Dutch working population. Besides practical

problems, employers' lack of knowledge is the main obstacle to employment for visually impaired people.

Additionally, people with a physical or sensory disability feel more lonely and participate less in leisure activities than people without a disability (Meulenkamp, van der Hoek, & Cardol, 2013).

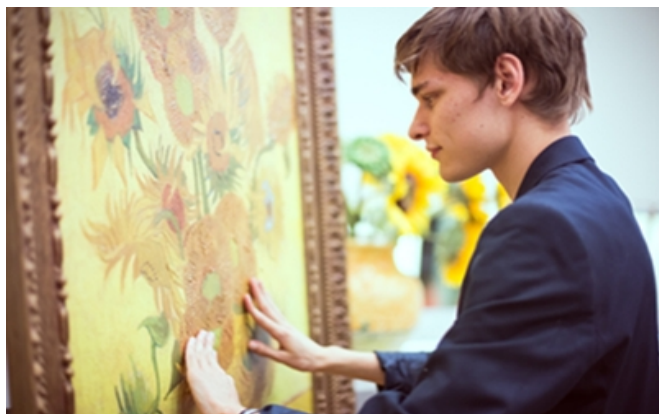
Feeling van Gogh primarily accommodates blind and partially sighted visitors. Most of them are accompanied by a sighted person, so they welcome an experience they can share. After all, a museum visit is a social outing for most of us. Therefore we wanted to develop a programme that is enjoyable for visually impaired people *and* their sighted friends, family, or companions. This approach not only makes Vincent van Gogh's work accessible to a new audience, but invites wider participation in culture and society.

Special need programmes are often developed without sufficient dialogue with the target population. *Feeling Van Gogh* was set up from the start in close cooperation with blind and partially sighted representatives of Dutch organisations in the field of visual impairment: Kubes (Art for the blind and partially sighted), Oogvereniging (Association of the Blind and Partially Sighted), and the Access to Culture project (European Blind Union). These organisations were involved from concept phase until launch, testing materials and advising on services, training of staff, and marketing. The programme was co-funded with a substantial financial contribution from the Oogfonds (The Dutch Eye Fund).

Star Material: Relievos

Premium quality relief reproductions of Van Gogh's paintings, called Relievos, were the

starting point of *Feeling Van Gogh*. The special “reliefography” technique combines a 3D scan with a high resolution print. The result represents the original painting as accurately and faithfully as possible, both back and front. The Relievos were developed by the museum and Fujifilm for commercial and educational purposes, but they proved to be star material for a programme for visual impaired visitors.



Blind participant touching a Van Gogh Museum Relievo

Van Gogh often used expressive brushwork in his paintings, and a technique calling for various layers of thick oil paint on the canvas. This painting technique is very suitable for 3D reproduction, making Van Gogh’s vibrant brush strokes accessible through touch for the first time. One of our visitors commented, *“I’ve never been able to see more than the difference between light and darkness. Because of that I’ve never been able to experience what’s depicted on a painting. The Van Gogh Museum Relievos are a great solution: I was able to touch the 3D printed paintings.”*

The tactile quality of the Relievos opens a new possibility for blind, and especially partially sighted people to discover Van Gogh’s art. But, feeling the brushwork alone will not give them a clear image of the work. It’s necessary to enhance the experience with explanation,

description, and other learning methods, focusing on the other senses.

Interactive and Multi-Sensory

In the Museum’s Department of Education and Interpretation we believe that we can create accessibility for our audience through an interpretative mix of various media. We look for an “educational mix” that dovetails with diverse learning styles, diverse senses, and diverse target groups. For our visitors with visual impairments, the diversity of eye conditions is well served by our policy to offer a rich variety of tools and media. By offering multi-sensory activities, where they can touch, hear, or smell, the participants make the paintings their own at their own pace, no matter what their impairment is. There is also a lot of room for interactivity between the educator and the participant, and among the participants themselves. Interactive guided tours are the Van Gogh Museum’s specialty, using amongst other approaches, Visual Thinking techniques.

Feeling Van Gogh is a two hour programme and consists of two parts: a guided tour through the museum galleries, followed by a multi-sensory session in our studio. For the guided tour, a group of 10-12 persons is taken by a trained museum educator (museum docent) through the galleries. They stop at the paintings that will be part of the multi-sensory session later on.

We trained a small group of our regular educators to give object descriptions. Some guidelines, drawn from Ginley (2015) include:

- Pay close attention to the speed at which you speak, and pace yourself.
- Use the basic information found on a label, such as the name, title or subject of the

object as a starting point before the description. The dimensions are especially important to give an idea of size.

- Use colour in the description, as many who have lost their sight retain a visual memory of colours, which will help to build up a picture of the object in their minds.
- Explain appropriate sounds, smells, etc., which relate to the object to make it come alive.



Guide dogs welcome!

Combining object description with interactive techniques, e.g., asking questions to spark a dialogue, makes it interesting to both the visually impaired visitors and their sighted companions. They can enjoy a museum visit together, and share the experience of the hustle and bustle of the galleries and standing in front of real icons, like Van Gogh's *Sunflowers*.

The second, multi-sensory session takes place in the quiet studio, away from the noise and crowded galleries. For this part, we focus on four paintings with thick, tactile brushwork: *Sunflowers*, *The Bedroom*, *Wheatfield under Thunderclouds*, and *Landscape at Twilight*. They are also key works in Van Gogh's story as an artist.

Participants are seated in two separate groups around tables. Each group focuses on two

paintings, and the museum educator introduces the Relievos and related materials.



Van Gogh's Wheatfield under Thunderclouds, painted a few weeks before his death in July, 1890

We offer:

- Artist materials, like the type of linen Van Gogh used for his canvases and a reproduction of his palette.
- Simplified relief images, which clarify the composition by eliminating the criss-cross brush strokes.
- Objects like a characteristic nineteenth-century Provençal vase, similar to the one depicted in *Sunflowers*. These pots were used to preserve duck's fat, and can still be found in antique shops. The texture of smooth glazing contrasting with the rough pottery provides a strong tactile experience and makes the painting come alive.



A Provençal pot from the nineteenth century, similar to the one in Van Gogh's Sunflowers.

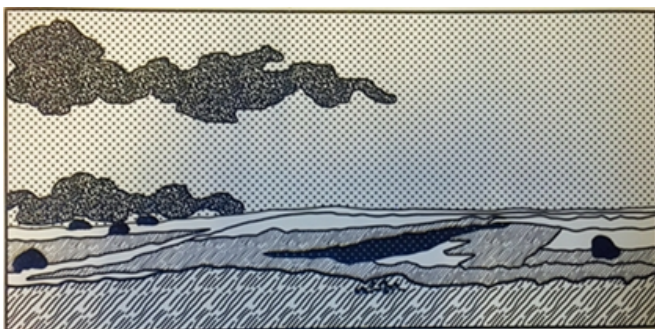
- A scale model of *The Bedroom* painting is our show stopper; people love it! It was made by someone who creates doll houses

and everything is there in detail: the bed, the little side table with the towel next to it, the paintings on the wall, etc.



Scale-model of Van Gogh's painting The Bedroom

- Reading aloud Van Gogh's letters to his brother Theo brings the artist himself back to life. He describes what he's working on, what colours he uses, and what he wants to express with his work. Getting close to Van Gogh's most private thoughts is an impressive experience.
- Last but not least, we have materials that tickle the senses. For instance, we use the scent of wet grass to enhance the overwhelming landscape of the *Wheatfield*, with its fresh green colours and hint of summer rain. The smell of clean, fresh sheets from the bed (mentioning jokingly that maybe Van Gogh's bedding wasn't that clean) is called up with a simple bar of Marseille soap. Through smelling we can evoke the places in Van Gogh's paintings.



Raised line image of Wheatfield Under Thunderclouds

Looking Back at the First Year

In March 2015 we launched *Feeling Van Gogh*, with four sessions a year. The press attention was impressive and they were fully booked within weeks. Quickly we added two extra dates. We received 71 participants in total, of which 38 were visually impaired and 33 were sighted. The fact that the sessions are free of charge with an admission ticket to the museum (17 €) may have helped to encourage attendance.

Prior to the launch, we organised two test sessions via blind organisations to see if our set up, tactile objects, smells, and sounds would meet their needs. 22 people participated. They gave good feedback and practical tips. Being together with sighted family or friends got a big thumbs-up, and so did the animated art conversation. Teaming up the museum's expertise on art interpretation with the expertise of the advisory group proved very efficient and cost effective (we didn't need to make any changes to the programme), and was the key to the success of the programme.

For 2016 we extended to 9 sessions, but they are already fully booked too. This means the need of blind and partially sighted people to participate in art and culture is huge. We now want to open the programme to paying (international) groups, and to visit schools and rehabilitation centres. We are planning a permanent area for an independent, multi-sensory experience.

Surprise

We set out to achieve some goals with *Feeling van Gogh*: to make art accessible to visually impaired people, to offer them the enjoyment of it, and in doing so add to their wellbeing. We succeeded in the first two, at least that is what

we can conclude from the participants positive reactions and the fully booked sessions.

Among the comments we received are the following: *"I had visited the Van Gogh Museum before, but it was mainly something that the other members of my family enjoyed and I was simply dragging my feet. This time I felt I was also participating and that was fun, because you really experience the museum a lot better."* *"It was really cool to experience the intentions of the artist. When I go to a museum I depend on the stories. Someone tells you what's on the painting. This time I could 'see' it myself."*

The last objective, to give a long-term positive boost through the art experience, is more difficult to research and evaluate. There are several studies in the UK on the effects of art on health and wellbeing (National Alliance for Arts, Health and Wellbeing, 2015; University College London, 2015). We are planning a research project on this subject in cooperation with the Reinwardt School of Arts.

Much to our surprise, we have achieved something else, something maybe as important as our original objectives concerning art and the blind and partially sighted. We have raised an awareness among the sighted! Our own museum colleagues, for example, wondered in the beginning why visually impaired people would be interested in visiting a museum. They now recognise how much it means to people with a disability. And most interesting, we seem to have raised an awareness with the next generation of museum professionals. We have been approached by several universities and art schools for visits and lectures on *Feeling van Gogh*. Students of art history, museology or social studies are the people who will be running cultural institutions of the

future. It's vital that they understand and have the interest of people with a disability at heart. As a large, international museum, the Van Gogh Museum has an exemplary role to play and we are happy to continue doing that.

Information or booking for foreign groups

Contact us at

vangoghopengevoel@vangoghmuseum.nl

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Educational Programme For Long-Term Patients with Cancer in the Southern Philippines

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Abstract

The Hospital Bound Educational Programme (HBEP) is an educational programme for children with cancer in a government hospital in Southern Philippines. The HBEP gives children undergoing treatment a chance to keep up with their schooling. The programme partners believe that bringing the school to the healing environment gives the children a sense of identity, hope for the future, and a feeling of being in step with the outside world.

Rationale

At the Southern Philippines Medical Center, there are children with cancer who reside in a transient home called House of Hope (2015) while undergoing treatment. In the years 2011-2015, 73 children were diagnosed with retinoblastoma, an eye cancer that begins in the retina among young children. They reside at the House of Hope while receiving long-term treatment at the hospital's Retinoblastoma Center. Volunteers working with the children realised that they received no schooling while undergoing treatment. The volunteers, being teacher trainees, realised that these children were being excluded from their fundamental right to education services, which is guaranteed by the Philippine government.

In 2012, University of Southeastern Philippines (USEP) conducted an evaluation of the feasibility of a hospital-based school. The

University determined that it was entirely possible, with support from the College of Education (Jalotjot and Gabales, 2013a). USEP has the capability and the necessary resources to run the project as an extension programme, since it is a teacher education institution that offers a Special Education programme. As a result of the study, the hospital-school model identified the children with cancer who reside at the hospital's House of Hope. The House is a temporary home for cancer patients and their guardians who have no place to stay during the treatment. It is managed and supported by a local Non-Government Organisation (NGO). The various stakeholders formed a partnership in order to establish the Hospital School.

Mode of Implementation

Hospital-based schools are for students experiencing problems in health and needing alternative schooling options. They provide learning programmes for children who are unable to attend or have limited access to an early childhood services because of illness.

The University took the lead in managing the hospital-based school. A committee composed of representatives from partner schools and volunteer organisations jointly manage the programme. Kindergarten and elementary pupils are officially enrolled at a public elementary school, while secondary school

students are enrolled at a public national high school. This ensures that educational needs of children with cancer who are undergoing treatment in the hospital are overseen by educators.

The Department of Education's Alternative Delivery Mode, particularly the Modified-In-School-Off-School Approach (MISOSA) for elementary level is employed for this programme. MISOSA is a teaching approach intended for school-age children who are pushed out of the regular system because of illness or other problems. Alongside MISOSA, the Drop Out Reduction Programme model is also utilised by the teachers in delivering the lessons for the secondary school students.

Face-to-face sessions are conducted on Wednesdays and Fridays, while activity days are scheduled every other Sunday. Summer Camp serves as an enrichment programme. Classes are held right at House of Hope. Teacher/Facilitators are the faculty and students of the University's College of Education, under the supervision of the Department of Education partners.

Resources and materials are donated by a business organisation and other donors. Instructional delivery is multigrade in nature, where students from different grade levels are grouped in one class and taught by volunteers who are expert in the subject area.

Table 1. Enrolment Data in the last three school years

School Year	Elementary	Secondary
2013-14	22	9
2014-15	12	5
2015-16	18	5

Lessons Learned

In 2013, which was Year 2 of the Programme, an evaluation of the Hospital-Bound Educational Programme showed that the partnership provided appropriate assistance to the learners in the programme (Jalotjot and Gabales, 2013b). The commitment and awareness of the local stakeholders in the BPEP created a strong, well integrated collaboration. There was high level of interest among learners, but the numbers decreased towards the end of the term, because of expiration or discharge from treatment.

In 2014, which was Year 3 of the programme, the Interactive Evaluation Study identified the factors leading to the success of the Hospital-Bound Educational Programme:

- Partners maintained a good relationship through constant communication;
- Partners and stakeholders are committed to attending classes and participating in activities;
- Stakeholders look at the programme as a personal advocacy;
- There is sufficient financial support from donors for books and materials; and
- The stakeholders consider the programme unique and commendable (Jalotjot & Gabales, 2014).

The 2014 Interactive Evaluation Study also identified obstacles and restraining forces:

- Teachers are stressed out and burdened;
- Some teachers are unable to attend classes;
- Some patients have low morale and opt not to join the educational programme;
- Parents are overwhelmed with financial burdens and are unwilling or unable to keep their children in the programme;

- Confusion caused by the Department of Education paperwork.

Finally, Zerrudo and Jalotjot's (2015) work with kindergartners with cancer in the Hospital-Bound Education Programme discovered that these pupils tend to have a positive outlook on their lives. Attending school in the HBEP may have contributed to this outlook, normalising their lives as much as possible.

Recommendations

After three years of implementation, the hospital-based school has contributed to the Philippine government's millennium development goals of providing education for all its children. Despite issues with instructional delivery, lack of materials, and some internal policies, the programme succeeded in providing education for long-term patients with cancer in the hospital.

However, a few components of the project may be enhanced to become more efficient and effective. More effort is needed to recruit volunteer teachers to teach in the House of Hope. Internal policy on teaching assignments need to match more closely with the circumstance of the hospital school. The Department of Education needs to increase administrative support and claim co-ownership of the project. Finally, the partnership with the local government unit and local volunteer NGO should be cultivated in order to sustain the success of the programme.

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Reaching Rural Families in Northern India

Javed Ahmad Bhat, Honorary General Secretary
National Association of the Blind, Jammu & Kashmir Branch, India

Jammu and Kashmir is a state in the far north of India, with the nation's highest percentage of persons with disability: nearly 3% of its population. According to the 2001 census, this almost half again as high as the Indian disability rate of 2.1%. Of these, 280,000 individuals in Jammu and Kashmir have vision impairment. Many thousands have additional physical, speech, or hearing impairments.

National Association for the Blind (NAB) recognised the unmet educational needs of the many children in the state with vision impairment and multiple disabilities (VIMD). As we embarked on the journey to bring the first-ever educational services to these children, we encountered numerous challenges. We had to solve problems of physical access, persuade families to accept our help, convince them of the need for educational intervention, and deal with the lack of availability of medical and therapeutic services across the state.

For help in meeting these challenges, NAB approached Perkins Voice and Vision India (PVVI), based in Mumbai. PVVI understands the need for educational intervention for these children, and our partnership gave us a new impetus and direction in our work. In addition to supporting us to initiate a home-based programme for educational intervention, PVVI also provided training to our teachers and physiotherapist. This training helped the entire team to conduct functional assessments of the children, provide educational intervention, and develop an educational programme with the involvement of families.

PVVI continued to assist NAB's work in Jammu and Kashmir through technical

support, onsite training, and mentoring. This partnership has consistently helped us improve our services, which is evident from the progress made by the children, and the growing acceptance and involvement of parents and families.

The journey of a thousand miles begins with one step! As I reflect today and look back, I remember the numerous challenges we encountered along the way as we initiated the programme. We began by visiting various villages, to meet with families of children with VIMD, and the overall community. Some of the main challenges we faced were:

Geographical access. Many children are in rural or semi-rural areas that are very inaccessible by any means of transportation. Additionally, the distances between one child's house and another's is frequently 15 to 20 km. This poses a huge challenge to the educators, who often have to travel long distances to reach a single child.

Poverty. Most of the families belong to the lower socio-economic group and some are below the poverty line. This means that the families do not have the money for adequate nutrition and/or medical support.

Physical space. Lack of space is a huge constraint. Some families have only one small rented room for the entire family. The educator has to work with the child in the same room where other family members are simultaneously performing various tasks.

Severity of the disability. Most of the children we work with have severe disabilities or challenges along with vision impairment. These challenges include cerebral palsy, severe

intellectual disability, hearing impairment, and/or other physical challenges. Some children have needs in the areas of feeding and associated behavioural challenges, which are often a result of the family's inability to communicate with the child.

Family issues. It is often difficult for the educator to gain entry in a home where the family is not aware about disability. Many families are illiterate and don't realise the importance of educational intervention for their children. In many cases even the basic care for the child is lacking.

This is when collaborative team work helps. The educators work in collaboration with the physiotherapist, other educators and the family members to figure out solutions.

In the home-based education set-up, the educator works with both the family and the child.



Acceptance by the family is the first step to gaining entry into the household. In addition to teaching skills, the educator also

needs skills to win the trust and build a relationship with the family. Often times the educator must understand and adjust to their preferences, language, routine, and culture. Once this relationship is established, it ensures that the family will be a partner in the process of education for their child.

Fortunately, the educators in our team have overcome most of these challenges. Today, because of their consistent visits, and the need-based educational intervention they provide, the families have an increased awareness about the unique needs of these



children with VIMD. The parents have learnt how simple things, such as supporting the child to sit in

the right position when feeding, working, or playing, can make a huge difference in the way the child participates in these activities.

As a result of the educational intervention, parents now understand the importance of having a routine for the child's toileting, bathing, feeding, and play activities. Many parents now interact with their children, as they have learnt to communicate through modes other than speech. Many children, who earlier did not enjoy the fulfilment of their basic needs, now have bathing, grooming, and feeding as a part of their daily routine. Earlier, many children wore the same soiled clothes for several days together; sometimes they would remain in the same position for several hours after they wet their clothes. All this has changed now, and an improvement in personal hygiene is very apparent in all the children. Also apparent is better nutrition; children get their food on time, now that their parents have learnt a proper routine for feeding.

Now all the families we work with are our partners in the process of educational intervention and rehabilitation of their children with VIMD. They treat the educator as a family member, and they are very happy to implement the recommendations.

Each educator has made a huge impact in bringing about a positive change in the thought process of families, improving the quality of life of the child. In short, the educators have indirectly ensured that the children have access to their basic rights.

The Vision Of Change: Nairobi Family Support Services

Edwin Mwaura & Stella Kamau, Nairobi, Kenya

Kibera is an urban slum and neighborhood of the city of Nairobi, Kenya, the largest urban slum in Africa. For 33 years, Nairobi Family Support Services has been serving its inhabitants.

Kibera is located five kilometers from the city centre. Its population estimates differ, ranging from one million to over 2 million households. Most dwellings are 12-by-12-foot shanties, with floors of dirt or concrete, walls of mud or iron sheets, and roofs of corrugated metal. Each shanty houses six or more people, with some sleeping on the floor. Kibera lacks a reliable clean water supply and sanitation facilities, and diseases related to poor hygiene are common, e.g. typhoid, cholera, and malaria.

Kibera's residents are poor and unemployed, and have little access to schools or health centers. Although Kibera lies on 2.5 square kilometers of government land, the government considers the inhabitants squatters, and provides few services. The great majority of the inhabitants rely on informal establishments for education and health services.



Panoramic of Kibera Slum

There are a number of charitable organizations that attempt to meet the needs of Kibera's inhabitants. Nairobi Family Support Services (NFSS) is a registered non-governmental

organization (NGO) started by parents of children with special needs. It was founded in 1982 with the support of Action Aid – Kenya. It serves families of children and young adults with special needs through comprehensive family-oriented rehabilitation services, with the goal of enhancing quality of life and self reliance. With a rehabilitation center in Kibera and another in Waithaka, Nairobi Family Support Services provides absolutely free services. NFSS is supported by donations from both national and international donors. Perkins International is one of the agency's main donors, supporting services for children who are visually impaired with multiple disabilities.

The programs of Nairobi Family Support Services empower children with special needs and their families. Services include early identification and intervention, screening and referral exercises, trainings, conducting occupational therapy sessions, provision of assistive devices, advocacy, awareness creation, school sponsorship, and an epilepsy outreach clinic.

In order to efficiently reach a vast majority of the marginalized groups in Kibera, especially children with disabilities, Nairobi Family Support Services has established a strategy to work with the local community. This strategy involves liaising with the village administrative council administration to identify local people who become community-based trainers. These people are well conversant with their surrounding environment, people, and culture, and are willing to work for the community. The trainings include: introduction to special

needs, early screening and identification, referrals and follow-ups, and a bit of counseling.



After the induction process, a community-based trainer ventures into

his/her village community and identifies families with children with disabilities. The trainer connects the family with NFSS for early intervention services. Among those identified, screened, and referred are children with visual impairment and multiple disabilities.

Faiz's Story

In 2011 a community-based trainer identified a visually impaired four-year-old boy named Faiz, and gathered background information by interviewing his parents. After his birth, they did not suspect that Faiz was visually impaired. During the crawling stage, his parents noted that he was constantly bumping into objects. However, Faiz learned to maneuver in his environment, and his visual impairment was not identified until he was screened by the community-based trainer.

Faiz was referred to Nairobi Family Support Service and Kenyatta National Hospital for clinical assessment, which confirmed that he is profoundly visually impaired. Through NFSS's outreach program, the trainer began working with Faiz and his family, using home-based interventions to develop his communication and daily living skills.

After some months, Faiz began attending an early childhood development center to improve his social skills, communication, and orientation and mobility. Within about six months, he transferred to Kilimani Integrated

Primary School, and was admitted in the beginners' class in the low vision section. Currently, Faiz is on pre-braille reading, undertakes his activities of daily living with minimal assistance, verbally expresses his needs, and walks independently in familiar environments.



Faiz and his family have regular follow-up meetings with the community-based trainer. This supports a smooth learning

transition from home to school, and vice versa. The community-based trainer also connects Faiz's family with other service providers, like government cash transfer for the marginalized groups.

Faiz's story is one of many. The work of the community-based trainers increases early identification of and intervention for children with special needs. The trainers connect them with service providers like health workers, nutritionists, and social workers, among others. Additionally, their efforts have increased awareness and acceptance of children with disabilities, and have reduced stigmatization of marginalized groups in society.

For 33 years, Nairobi Family Support Service has stayed firm in the Kibera slum, providing quality rehabilitation services. NFSS has empowered well over 2500 children with special needs and their families. 1500 locals have also benefited by being trained as qualified community-based trainers. The theme of January 2016 issue of *The Educator* matches the slogan of Nairobi Family Support Services: **“reaching the unreachable.”**

Marrakesh and Bookshare: Ending the Book Famine

Jim Fruchterman, CEO, Benetech, United States

Introduction

There is a global book famine for people with visual impairments. Ending that book famine is now well within reach. This article outlines the path to providing equal and independent access to books for the community of people with visual impairments. Central to this journey is reaching the unreached: the great majority of people, especially in less developed economies, who have never had independent access to books.

The DAISY Consortium of libraries serving people with print disabilities (visual, learning, and physical disabilities that interfere with reading traditional print) outlines this goal as “making the same book available for everyone at the same time without extra cost.” In the United States, we are getting close to reaching this goal. Now, we have to extend this to the entire world!

The keys to reaching this bold goal are three major innovations: in law, in technology, and in implementation. These innovations have already been demonstrated to work in some countries, and I believe they are ready to be extended to the world.

Furthermore, Benetech, the nonprofit that operates Bookshare, currently the largest specialised library for people with visual impairments in the U.S., is ready to extend our reach to the rest of the world, with a special focus on reaching the unreached in developing economies.

Innovation in Law

The first critical innovation is a globally effective copyright exception. The difficulty of obtaining permissions to create accessible versions of books in some countries has been a large part of the book famine. And cross-border permissions are even more difficult.

Luckily, the advocacy of the World Blind Union and other organisations in the VI (vision impairment) field have led to the negotiation and signing of the Marrakesh Treaty by over 80 countries in 2013. In order for the Treaty to go into effect, ratifications are needed by 20 more countries. We expect this to happen in 2016.

In short, the Marrakesh Treaty makes it legal for an individual with a visual impairment, as well as educators, schools, and organisations serving this community, to create accessible copies of printed materials without needing to obtain permission. You can simply make a book available in braille, large print, audio, or ebook format, if it is needed by a person with a print disability (although this article focuses on people who are blind or have a visual impairment). In the great majority of countries, you will be able to do this for free.

Furthermore, it will be possible to provide a copy of that accessible book to the people who need it in other countries that have ratified the Marrakesh Treaty.

The Marrakesh Treaty is an incredible breakthrough for our field as it provides the legal innovation needed. If your country hasn't ratified it already, I encourage you to join with

your national World Blind Union affiliate to help advocate for this!

Innovation in Technology

The second critical innovation is the advancement of technology that eases the process of creating accessible books and consuming them (that is, reading them). Thanks to the technology industry as well as the DAISY Consortium, these advances have already occurred.

The power to create accessible books is now in the hands of just about everyone with access to a computer. It's easy to scan a printed book into text file with OCR, or to record a book with a recording application. And this kind of technology is freely available or inexpensive.

Standardised formats have been aligned to make it simple to share accessible books across devices and the world. Audio books are all in MP3 formats. Text ebooks are in common formats like EPUB or DAISY.

These standardised formats can now be read on specialised devices designed for people with visual impairments or with the standard PCs, tablets, smartphones or even feature phones and inexpensive MP3 players. Braille and large print physical books can be easily produced from digital master copies.

Essentially, it should be possible for every blind or visually impaired person in the world to have a device that allows them to read independently.

Innovation in Implementation

The third critical innovation is revolutionising the ways accessible books are produced and distributed.

Crowdsourcing is an example of a new approach to accessible book production. Until recently, human-narrated audio books had to be produced almost exclusively in purpose-built recording studios. Now, more and more audio books are being produced in homes with high quality, yet increasingly affordable, recording equipment. Our library, Bookshare, was initially created by blind people scanning books for themselves, and then sharing them legally with other members through the Bookshare website. A single individual contributed over 3,000 scanned books to Bookshare the year it was launched!

Next, it is now possible for the publishing industry to directly benefit people with visual impairments. Publishers are now standardising a format that is very close to the DAISY format, the leading disability-specific content format. The barrier that was preventing publishers from engaging with the community has now fallen, and many publishers are willing to help.

Lastly, the traditional approach of circulating physical media through postal channels has had huge limitations in terms of meeting the needs for books. Digital technology means that it is simple to deliver an accessible book anywhere in seconds via the Internet. It is also easy to make multiple copies of the same title for almost no cost.

The Impact of These Innovations

These parallel innovations are coming together to end the book famine. By making it legal, technically feasible, and operationally practical, it will become possible to get accessible books to the people who need them most.

Cross-border sharing is an example of a new implementation option made much more practical through legal and technical innovation. It is increasingly legally possible through copyright permissions, and eventually through widespread implementation of the Marrakesh agreements. The technology already makes it as easy to deliver a digital accessible book to one country as another, assuming the legal and operational aspects are addressed.

These innovations, especially when working together, drive the cost of providing accessible books down dramatically. Services to people who are visually impaired are traditionally underfunded. However, it is now possible to imagine solving the book access problem with funding that is within practical reach.

Ultimately, universal design, combined with these innovations, may enable us to completely abandon the system of specialised accessible books. As the ebook displaces the traditional printed book in the publishing industry, we reach a turning point. Amazon.com, the largest bookseller in the United States, announced that it has been selling more ebooks than printed books since 2011.

The ebook, unlike the printed book, is intrinsically as accessible to a person with a disability as a person without one. It is ironic that anti-copying technology on ebooks often has the effect of locking out the most natural customers for ebooks, people with visual impairments. George Kerscher is the DAISY Consortium's Secretary General, and one of the world's top experts in accessible books. He and I coined the term "soundproofing the book" for this unfortunate practice. Our goal is to ensure that commercial ebooks are fully

accessible to people with disabilities with the Born Accessible campaign. Our motto is "If it's born digital, it should be born accessible!" Of course, this last innovation isn't fully developed, even in the United States, which has the most advanced ebook publishing industry.

Bookshare: An Example of the Three Innovations Working at Scale

Thanks to these innovations, the book famine has effectively been ended for students with visual impairments in the United States. For example, Bookshare has made a promise to all American students with print disabilities: if you need a book for your education, and we don't already have it in our collection, we will get it and add it. Of course, with 385,000 titles already in our collection, the odds are very high that a person with a visual impairment will find that the specific book they need is already available.

The success of the Bookshare model has been made possible by combining all of the innovations described above. The Marrakesh Treaty was modeled after the U.S. copyright exception, and Bookshare was probably the most commonly cited example in the negotiations of what the Treaty would make possible.

Reaching the Unreached

As you can see, these innovations make solving the book famine possible globally. It is possible to meet the needs of a single blind person for a given book today. But, to truly have "the same book available for everyone at the same time without extra cost," we will need to cooperate more across borders. Once an accessible book is created, it shouldn't be necessary for somebody else to duplicate that

work. That was the dream behind the creation of Bookshare. And, that dream is ready to become a reality globally.

The Bookshare Offers

Bookshare has two key offers to make to the field of education for students with visual impairments. The first is access to the existing Bookshare collection. The second is assistance in building a national collection in a place where the infrastructure doesn't yet exist.

Our first offer is to make Bookshare available to students today. Bookshare is being used by visually impaired people in more than 50 countries. Thanks to funding from the U.S. government and key donors, we can effectively subsidise the cost of providing Bookshare. In countries classified as Low or Low-Middle Income by the World Bank, Bookshare is US \$10 per year. And, if affording these modest fees is a challenge for students in these countries, we could probably find funding to underwrite these services.

Our existing collection of more than 200,000 titles available worldwide is very strong in English and Spanish, and is quite useful for English speakers and students in higher education. At present, Bookshare does not have the most important textbooks needed for primary and secondary education outside the U.S. However, given that English is an important language of instruction in higher education in many countries, many of Bookshare's higher education titles are useful worldwide. For many educators, the existing Bookshare collection will be an important secondary resource of English language literature. However, in some countries, it may simply be the only significant source of accessible books.

The second offer addresses the most important need of students with disabilities, especially those in primary and secondary education. These students need their locally important educational and vocational content, in their mother tongues. Since these titles are different in each country, or even at the state or provincial level inside countries, this is a problem that needs to be addressed locally. But, Bookshare has a bold offer to help with this challenge.

Thanks to new and existing funding from donors in wealthier countries, Bookshare is offering to partner with up to three interested and engaged countries to lend the Bookshare infrastructure for free for a period of two years. We will look for in-country partners who share our commitment to providing books to those with print disabilities. Our focus is on reaching students in Low or Low-Middle Income countries that have ratified the Marrakesh Treaty.

Here are the key elements of this offer, for these countries:

Free Bookshare library membership for all schools, educators and students, for the purpose of solely serving students with print disabilities, especially students with visual impairments, including availability to over 200,000 English and Spanish ebook titles.

We will add 125 local books from the country to the Bookshare collection that are not already in Bookshare. We will need copies of the print books that are scannable using optical character recognition (or we can work with local publishers to obtain digital copies). This will include the top 50 children's titles, the top 50 literature titles, and the top 25

primary and secondary textbooks needed by students with disabilities.

We will also create teacher training materials in the form of webinars to help educators learn how to enroll students in the service, how to utilise assistive technology for reading the books, and how to add scanned books to the Bookshare library.

At any point, any organisation in the country meeting the Marrakesh definition of an authorised entity will be free to access master copies of all materials added to Bookshare under that country's national copyright exception. We do not want partners to be locked in to working with Bookshare indefinitely, especially if a country is able to later create its own national digital accessible library infrastructure.

We at Bookshare want to help make more books available. We are happy to talk to leaders in the field of educating students with visual impairments in any country about how

to do this. We are confident we will be able to find greater cross-border support for these efforts, given the priority the world has placed on the issue through the Marrakesh Treaty.

Conclusion

Ensuring that people worldwide with visual impairments have access to the books they need for education, vocation, and social inclusion is now within reach. The legal, technical, and implementation innovations that will make this possible have already been developed and proven. The digital ebook is especially important for advancing this cause with the full range of formats, including braille, large print, and audio.

As a nonprofit agency organised with a global charter to serve people with disabilities, helping end the book famine is a central mission objective for Benetech. We look forward to helping the field advance this shared goal of full equality of access to books.

Partners of ICEVI - Nippon Foundation Higher Education Project



Krousar Thmey
Cambodia
www.krousar-thmey.org



Resources for the Blind, Inc.,
Philippines
www.blind.org.ph



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(Indonesian Blind Union),
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www.saomaicenter.org



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Lao Association of the Blind
Lao PDR
www.lablao.org

Reaching Australians with Vision Impairment: The New National Disability Insurance Scheme

Sue Silveira, Royal Institute for Deaf and Blind Children,
Renwick Centre and The University of Newcastle, Australia

Introduction

Australia is a country of 24 million people, with an estimated 4 million people having some type of disability (Australian Bureau of Statistics, 2009). Of these, 357,000 people (or 1.4% of the Australian population) are reported to have low vision or blindness (Vision Australia, 2013). Until recently, people with disability were offered services under a scheme known as the National Disability Agreement. This federal government program included support for their accommodation, community access, respite care, employment, and advocacy assistance (Australian Institute of Health & Welfare, 2013).

The National Disability Agreement was highly criticised for failing to prevent many disadvantages for people with disability and their families (Australian Government, 2014). In response, the Australian Government, in consultation with people with disability, adopted a new and innovative scheme. The reforms of the National Disability Insurance Scheme (NDIS) have been rolled out progressively, improving the support available to all Australians with disability (aged 0-65 years) by 2018.

The NDIS focuses on minimising the impact of disability (Australian Government, 2013a). This goal will be achieved by shifting the focus of disability support away from the *presence* of a health condition to the *impact* of a health condition, specifically on communication,

social interaction, learning, mobility, self-care, and self-management (NDIS, 2014). As vision impairment has a great impact in most or all of these areas, it is included in the group of disabilities eligible for NDIS support funding.

Eligibility for NDIS support will be determined using a designated assessment tool. Given the NDIS focus on the *impact* of disability, it is reasonable to expect that this tool would include a *functional impact* assessment. Instead, a visually impaired person's eligibility is judged using the clinical measurements of an ophthalmological examination. However, it has long been known that clinical measurements are poor indicators of the functional impact of vision impairment (Colenbrander, 2010). This outmoded assessment process is creating a serious misalignment between the widely acclaimed NDIS philosophy of support for the functional impact of disability and the methods of assessment of eligibility for that support (Silveira, 2014).

This paper will examine the evolution of the NDIS, the potential problems arising from its current eligibility criteria, and potential solutions. The goal is to ensure that NDIS disability support meets the functional needs of Australians with vision impairment.

The Evolution of Disability Policy in Australia

Western societal approaches to supporting people with disability have historically been

influenced by the “medical model.” Urdang (1983) describes the medical model as “the traditional approach to the diagnosis and treatment of illness as practiced by physicians... focussing on the physical and biological aspects of specific diseases and conditions” (p. 662). However, many criticise the application of this model to disability services and supports. For example, the American social scientist Wolfensberger (1975) summarised the unsuitability of applying a medical model to a disability context. He points out that the system identifies disability as a disease requiring a “diagnosis and prognosis” (p. 5). Taylor & Hawley (2010) have similarly criticised the application of the medical model to disability generally, because it creates disempowering attitudes and reactions to people with disability.

The World Health Organization (WHO) has provided leadership in addressing the need for the de-medicalisation of disability, beginning in 1980 with the release of the International Classification of Impairment, Disability and Handicap (ICIDH). The ICIDH heralded change, but did not recognise the role played by the disabled person's environment, and “the associated need for interventions focusing on changing the physical, social and policy environments in which disabled people live, rather than the individual” (Schneider, et al., 2003, p. 590).

The fallout from discussions about the ICIDH's efficacy led to the redefinition of disability. Hurst (2003) defines disability as “the outcome of the interaction between impairment and functioning and the environment (p. 574). Simeonsson, et al., emphasize disability's multi-dimensional nature in the form of “impairment, performance

limitations and the experience of disadvantage” (p. 602).

The World Health Organization revised the ICIDH, and released the International Classification of Functioning, Disability and Health (ICF). This international framework described and measured health and disability (WHO, 2002). The ICF signalled a conceptual shift to represent disability as an outcome of interaction between health conditions and contextual factors, including environmental and personal characteristics (WHO, 2002).

By implementing the National Disability Insurance Scheme, Australia has abandoned the medical model, moving to an approach informed by the ICF framework. As such, when assessing the needs of a person with disability, the NDIS assessment tool uses a strength-based approach, which focuses on supporting the client's goals and aspirations (NDIS, 2014).

The organisation of the new NDIS assessment tool reflects the domains of the ICF and includes the following:

- Learning and applying knowledge;
- General tasks and demands;
- Communication and mobility;
- Self-care and special health care needs;
- Domestic life activities;
- Interpersonal interactions and relationships;
- Community, social and civic life;
- Education and training;
- Employment.

Australia has historically responded to global initiatives in disability policy. We've seen the establishment of the Australian Human Rights Commission in 1981; the Commonwealth

Disability Services Act in 1986; The Disability Council of NSW 1987; the Commonwealth/State Territory Disability Agreement in 1991, the national framework for the delivery, funding and development of specialist disability services for people with disabilities (Australian Government Department of Social Services, 2013); and the Commonwealth Disability Discrimination Act in 1993. Australia was also a signatory to the Convention on the Rights of Persons with Disabilities (2006). These gains for our nation's disability policy sector, including the recent implementation of the NDIS, place Australian policy on track with major current global initiatives.

As laudable as these steps are, policy alone is not enough to ensure that support reaches those it is intended to reach. To guarantee that NDIS objectives are met, service provision methodology must address the impact of disability. In the case of vision impairment, using clinical measurements as eligibility criteria for NDIS support falls short of achieving this highly important goal.

NDIS Eligibility Criteria Barriers

The issue of whether or not clinical measurements truly represent a person's visual function has long been debated in the literature. There is no doubting the vital role clinical measurements play in the diagnosis and management of eye disease and vision disorders (Blais, 2011). However, the ophthalmic literature does not espouse the use of clinical measurements to calculate disability funding. Such literature acknowledges that ophthalmic assessment often occurs in an optimised environment where short measures of vision are taken that do not replicate the visual challenges of the everyday environment

(Blais, 2011). For example, such significant real-life issues as visual clutter and glare are controlled within an ophthalmic setting. In other words, clinical measurements reflect scores achieved in an environment that does not represent the one that the person functions in from day to day (Colenbrander, 2010).

Two other key issues for people with vision impairment are visual fatigue (Holbrook, Koenig & Rex, 2010), and fluctuations in visual function. People with vision impairment experience these fluctuations due to variations in lighting, personal stress, and general wellbeing (Sticken & Kapperman, 2010). A formal ophthalmic assessment is a series of precise clinical measurements that reflect the threshold of a person's visual function. Because the assessment is conducted in an ideal, controlled environment, it doesn't measure the impact of such factors as glare, visual clutter, visual fatigue and fluctuations in visual function. This brings into question whether or not these measurements are truly representative of a person's visual function in the daily environment.

For people with visual impairment, the reliance on clinical measurements as eligibility criteria potentially creates a barrier to acquiring NDIS supports. There is the attendant risk of NDIS underfunding or not funding needy Australians with vision impairment. For example, a person with oculocutaneous albinism may be diagnosed with mild vision impairment during an ophthalmic assessment conducted in a controlled lighting environment. However, the same person will experience a significant visual impact from glare that naturally occurs in their everyday environment (Phillips, 2012). This leaves them with more severe vision impairment than is indicated by their clinical measurements. Another common example is a

child with cortical vision impairment who demonstrates an adequate level of visual acuity in an ophthalmic setting, but does not display a similar level of visual function in an environment that has visual clutter and glare, such as a classroom.

Solutions to Ensure the NDIS Reaches Needy Australians with Vision Impairment

The aim of the NDIS is to ensure that Australians with disability receive the funded support they need and deserve, empowering them to participate in and to contribute to social and economic life to the extent of their ability (Australian Government, 2013b). To promote this aim for people with visual impairment, a reform of the eligibility criteria for NDIS funding is clearly necessary. However, introducing this reform is not without its challenges. Currently no validated assessment tool exists for efficiently evaluating the impact of vision impairment on a person. However, significant reference points exist within the low vision literature that could be invaluable to this reform.

The current practice of using clinical measurements to assess a person's visual function and their level of vision impairment results in a narrow view of how the person sees. A broader understanding comes from examining the components of the person's visual function, which includes factors such as glare, visual clutter, visual fatigue, and fluctuations. Corn (1983) for example, has de-constructed visual function into its components: visual abilities, the visual environment, and key individual traits of the person. All of these influence the person's capacity to use their vision at any given time. This sort of thinking might drive a reconceptualisation of visual function, and

importantly, guide development of more suitable eligibility criteria.

Another useful methodology is to examine the impact of vision impairment on the person's quality of life (QOL). Validated QOL measures exist, and some low-vision service providers use them in place of clinical measurements when assessing eligibility. Examples of QOL instruments include the National Eye Institute Visual Function Questionnaire, developed for the assessment of vision-targeted, health-related quality of life measures (Mangione et al, 1998); the Assessment of Function Related to Vision, which tests a spectrum of vision-related activities (Seo, Yu & Lee, 2009); and the Massof Activity Inventory, a task-based tool that broadly evaluates the goal of the person, the task, and the function needed to achieve the task (Massof et al, 2007).

Finally, there is much to be learned from educators who support children with vision impairment. They are often privy to ophthalmic reports that include clinical measurements, but recognise that these measurements do not necessarily define the child's visual function (D'Andrea & Farrenkopf, 2000). They are often experts at implementing strategies to minimise the impact of factors that affect visual function, while maximising the residual vision of the child. Their practice provides many examples of strategies that can reduce barriers to ensure that support reaches children with vision impairment.

Conclusion

With the recent implementation of the NDIS, Australia has attempted to create a disability support scheme that empowers people with disability (Australian Government Department of Social Services, 2013). There is no doubt

this aim should receive wide applause. But to realise this aim, all aspects of the NDIS must align. This paper has questioned the nature of the existing NDIS eligibility criteria used for persons with vision impairment. More work needs to be done to develop equitable and informed eligibility criteria that will reveal the full impact of a person's vision impairment, and the true nature of their visual function. This will ensure that the NDIS provides appropriate levels of support to all Australians with vision impairment.

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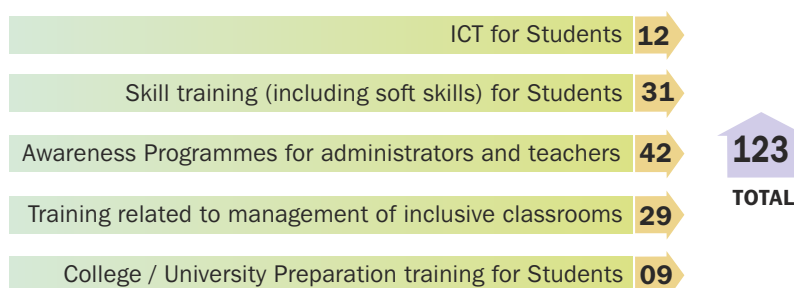
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ICEVI-Nippon Foundation Higher Education Project

Capacity Building Activities

To date, project partners have organized a total of 123 capacity building activities to both enrich the educational experience of students with visual impairment and to eliminate barriers and create more inclusive learning environments and policies for all students. Most of the training activities organised for students included a component on preparation for university education and at the same time, some exclusive programmes focusing on preparation for university education were also organised. The figure below illustrates the type of capacity building programs that have been carried out.



The Right to Live Independently and to be Included in the Community

Victoria Belen Pérez & María Verónica Cajal, Córdoba, Argentina

For those of us in Latin America who have family members with severe disabilities, independence and inclusion are matters of great concern. The U.N. Convention on the Rights of Persons with Disabilities, Article 19, declares the rights of all people to live independently and to be included in the community:

States Parties to this Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community....

Families of Adults with Deafblindness or Multiple Disabilities

Attaining an independent adulthood is a challenge for persons who have deafblindness or multiple disabilities, given that they need help and support for nearly every activity of their lives. Most tasks, even many simple ones, require the assistance of another person. Independence and inclusion are the main objectives of the Association of Parents of People with Multiple Disability or Deafblindness in Argentina (APPMDD). We work to create and maintain spaces where these adults can live independently and be included in the community. We have sponsored legislative bills in the Argentine Congress in 2012 and 2015. We have also

collaborated in legal actions with the disabled in specific and urgent cases.

The reality is that medical coverage is selective for paid professionals, such as therapeutic companions, guidance, facilitators, interpreters, and other systems of support. Financial coverage is granted in very few cases, which means there is little support for an autonomous, independent life for people with disabilities. This means that a real, functional support system is contingent on the family's ability to maintain it. Although the goal is independence, people with disability rely on the presence and support of their relatives throughout their lives.

Because so much depends upon the families, they must prepare for their children's adulthood years from the time of birth. We could easily argue that those who fail to prepare may later become an obstacle for their own child's independent future.

Aside from the lack of resources, families encounter other problems as they work for the independence of their children with disabilities. There are many emotional conflicts, as parents often consider self-sufficiency something very difficult for their children to achieve. On the one hand, independence is their greatest desire, but on the other hand it is also their deepest fear.

Mixed feelings overwhelm families for whom everything has become harder with the arrival of a child with disabilities. They have been constantly fighting for them and next to them

for years. For this reason, it's hard to get used to the idea that their disabled relatives may one day be self-determined and fully included in the community. Additionally, the cost of living for a disabled person living on their own is sometimes impossible for the families to afford, even though it may be their ultimate desire.

The Networks

Complying with the UN Convention on the Rights of Persons with Disabilities is the responsibility of national government. This government support is particularly necessary for Article 19's rights to independence and inclusion, particularly for citizens with severe disabilities, such as deafblindness or multiple disabilities. However, it is the family unit that must take on most of the responsibility for ensuring that a disabled person engages with the opportunities for participation that are available. Too often, overwhelmed family members miss these opportunities. Sometimes their participation during the school years is rather passive and secondary, exactly when the groundwork for the future independent life of the child must be constructed.

The truth is that nothing in this life can be made being alone, for it is always necessary to count on the backing of a network that includes a support system. Families must work jointly with every area and agency. This encourages future independence, but it is a task that is impossible to accomplish without help. It is precisely here where the term of *support networks* makes sense. A new National Education Law has put forward in Argentina, constructed to be totally flexible to the needs of persons with deafblindness and multiple disabilities.

It is important to mention that backing configurations:

... are Networks, relations, positions, interactions among people, groups or institutions that are conformed to detect and identify barriers to learning and develop educational strategies for scholar and community participation. Practical configurations that can be adopted by educational support systems are: attention, counseling and orientation, training, provision of resources, cooperation and coordinated activity, monitoring and investigation.”
(Argentina Ministry of Education, 2009)

The policy quotation above show why networks constitute a key element when it comes to the realisation of the goals of Article 19.

Life Stories: Victoria Belen Perez

My name is Victoria Belen Perez. I am from Córdoba, Argentina, and I am 24 years old. I am a collage student in the fields of Psychology and Human Resources separately, and I am the younger sister in a family of four children. My sister Natalia, 41 years old, is deafblind and has multiple disabilities. She is the reason why I am writing this; to briefly tell her still ongoing life story.



Four years ago, a residence for women with deafblindness and multiple disabilities opened in Córdoba. My family and I never thought that this would ever be a reality. Finding independence for Nati had seemed like an impossible dream, and we were afraid that she would never be able to move away from home.

After considering the setting, we decided that Natalia should live with another person with the same condition. It was not easy, either for her or for us, to get used to the fact that she would no longer be at home everyday. She would only come to visit during the weekends, although we would be able to see her whenever we wanted during the week. Still, it was incredibly hard for us all, and it took us time to adapt to this change as well as to accompany her through this process.

Nati lived in the residence for three years. It was for all of us a great experience to see her in contact with other people besides her family. Unfortunately, given the huge economic cost of the residency, Nati couldn't continue to live there. She is currently living back at home with her family.



I want to make clear that my family, like that many other families, would love to once again see Nati have the opportunity to live independently. We

hope that independence and progressive inclusion in the community will become a priority for the multiple disabled and the deafblind. It is a challenge for society to address the economic demands of this work, and to develop an infrastructure that supports

residences and services needed for independent life.

Life Stories: Maria Veronica Cajal

My name is Maria Veronica Cajal, and I live in Córdoba, Argentina. I am 52 years-old, married, and mother of five children. The oldest of them, 27 years-old, is a fully dependent man. He is in a special residence for persons with multiple disabilities because of his condition, which requires permanent assistance. We made the decision to place him there after considering medical advice, and because it was impossible for the family to assist him 24/7 and provide him of all the services he needs.



The UN Convention introduced a new concept of personhood and rights for people like my son. It brought us new considerations regarding his right to live independently with an adequate support system. It encouraged our family to develop new ways for our son to participate in social, sports, cultural, vocational, and educational activities that his community offers. We found that therapeutic companionship is among the most significant forms of support for dependent people, encouraging activities independent of the rest of the family.

In our case, we have arranged a mutually beneficial agreement with a school that trains therapeutic companion professionals. They

assist our son respectfully through the activities and decisions of his adult life. It has also been necessary to set up activities outside the residence in a systematic and regular basis. We use a reliable and adequate transportation service that is prepared for such a task. Furthermore, we activated social networks around him, which engages him in activities inside his community.



Family is part of the support system for adults with disabilities. Its function is to assist and provide resources, services, legal representation, health insurance, as well as social and vocational activities. This creates a sustainable network around a young man whose independence requires the investment of resources of every kind. In Argentina, laws



have supported such projects for independent life, but the funding provided has been very limited. This means families have no choice but to face this economic burden

on their own, or give up on the idea of ever achieving this important goal. Additionally, there are very few stories of disabled persons that have succeeded in becoming independent. Under the current circumstances it is almost unaffordable for most persons with multiple disabilities.

It should be made clear that in Latin America it is not looked upon kindly when a family allows a person with multiple disabilities to live on their own. Mothers, above all, feel terrified with guilt. Many believe that nobody will be able to understand and assist disabled children other than their own mothers. Our society expects an eternal attitude of service from mothers, as if they were the ones to blame for the multiple disabilities experienced by their children.



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A Model Supporting Children, Families or Colleagues in Remote Areas

Juventine Imanitai, Deputy Head Teacher, St. Francis Secondary School for the Blind, Uganda

Accessing education and payment of fees

In Uganda, the literacy and numeracy levels are very low. To improve this situation, the government of Uganda introduced Universal Primary Education (UPE) and Universal Secondary Education (USE) in 1997 and 2007 respectively. Literacy and numeracy is especially low among marginalised groups, such as persons with disabilities, who constitute a good proportion of the population, especially in deeply rural areas.

The Universal Education enactments are intended to promote equal access to education for all persons irrespective of their status. Over the years, this programme has been running successfully amidst a number of challenges. This paper will focus on the problems of supporting children who are blind or visually impaired and families in remote areas. We devised and would like to share some innovative approaches that address the financial difficulties of education in rural and impoverished parts of the country.

According to the Universal Secondary Education (USE) policy, the government and the family each has a role to play in supporting a child's education. The government supports the infrastructure, pays staff salaries, and provides instructional materials. The family is responsible for food, uniforms, scholastic materials, as well as accommodation or other boarding arrangements. However, the public has mistaken the concept of “Universal Education” for “free education,” causing

parents to pull away from their share of the financial obligation. The situation is even worse for children who are blind and visually impaired. The combination of this reluctant attitude and poor economic status has made education for such children nearly impossible in Uganda.

This situation creates great problems for the students of St. Francis Secondary School for the Blind. We are a special school in Uganda that enrolls boys and girls aged 14 to 21 years from all over the country. We implement the Universal Secondary Education programme, providing a formal secondary curriculum, with vocational and life skills training. Most of our learners come from very needy families, whose parents or guardians in most cases are themselves blind or visually impaired. This creates difficulty in matters of support for the learners. As a consequence the children drop out of school prematurely, and others miss out on the opportunity for education completely.

Model for success

At St. Francis, we have been very concerned about this problem. After lengthy consultations with the concerned families, local authorities, and other stakeholders, we devised a solution. We created a method of permitting parents and guardians of such needy children to contribute fees in kind. They are required to provide whatever is available to them, as long as it is of value to the school. Payment in kind can be in the form of food, fuel material like firewood and charcoal, or construction materials like pit

sand, baked bricks, or stone chips, to mention but a few possibilities.

In one case, the school purchased some equipment needed by a visually impaired parent who is a stone quarrier. In return, he provided his products at market prices to the school for its construction projects. This enabled him to pay in kind the educational fees for his children. This particular family has managed to get an education for five of their seven visually impaired children through St. Francis Secondary School for the Blind. Two of the students have graduated from the University, one is a teacher and two others are students in other institutions of learning, with support from persons of good will. The beauty of it is that, in addition to providing an education for their children, the family has built enough capacity to continue with its business. This will enable them lead a decent life as a family as long as they continue having energy.

We wish to promote this idea to other school administrators, who certainly encounter similar situations in their localities. Accepting payment in kind with materials needed by the institution permits families to educate their children with dignity. At St. Francis School we have sometimes had to be flexible and go the extra mile. At times, some of the parents could not even provide fees in kind. We created a way for them to exchange their time and energy by doing work needed at the school. We negotiated the value of their work, and counted it as a payment for their children's school fees. This method has enabled a good number of parents to see their children through a complete education cycle, with no barriers.

Whereas there is a lot of glory in the model, it has come with a series of challenges.

Accepting payment in kind reduces the cash income and has an impact on budget formulation and implementation. You cannot effectively plan for the use of what you don't have at hand, especially before you negotiate with the family. This means a lot of budget review has to be done from time to time. It is even trickier when the process involves several stake holders. Further, because we enroll students from throughout the country, it is a strain on our time and resources to administer the processes of identification, sensitisation, implementation, and follow-ups.

This approach also calls for a lot of patience, as the delivery time for the items or services is never perfect. Delivery is based more on the ability and convenience of the supplier than on the school's needs. Such a system compromises expectations in modern management where time is a critical aspect. This situation demands a lot of substitution, meaning that other alternatives must be readily accessible.

Quality control is highly compromised because you are always pressured to accept whatever is delivered, regardless of the state. In most cases no room is left for you to make a choice. The emphasis here is more on the type or name of the item than its form. After all, the parent can only provide whatever is available to him/her irrespective of the quality. Sometimes at the end of the game there was no value for money.

The benefits of this payment-in-kind approach, however, outweigh its drawbacks. Most notably, it has increased access to education. It has also created loyalty, support, and appreciation for education among the parents. The dependency syndrome is progressively disappearing. This policy has promoted confidence among the families as well as the

children, because they are sure of getting access to school without limitations. It renders education a service to be enjoyed by both the poor and the well-to-do.

Enrolment has grown, and the school has enjoyed increased parental support. Families' attitudes about education for their children with visual impairments have improved. Ultimately, life has become more meaningful for our students with blindness and visual impairment. There is more hope, especially for independence in the life to follow after school.

Students' absenteeism as well as the school dropout rate have drastically decreased. The teacher-learner contact time has increased due to the progressive decrease in the drop-out rate caused by school fee defaults. Improved attendance has translated into improved academic performance, acquisition of skills, and above all, increased positive behavior change. Ultimately this has a positive effect on community social welfare.

Parents have exhibited a higher level of responsibility, now that they are fully responsible for the education of their children, as well as the resources in the respective localities. Equally they are invested in the existence and development of the school, which never used to be the case.

As a result of their educational achievements, people who are blind and visually impaired have greatly increased their level of participation in community activities. Some of our graduates are already participating as the main bread winners in their families. Others have seriously taken on the political and

religious life of their areas. A good number have joined the field of music, dance, and drama, which enhances the cultural and recreational environment of their communities.

Obviously harmonious integration of the blind and visually impaired in the communities is an achievement worth celebrating. Marginalisation based on disability has decreased to a reasonable degree. People who are blind are less likely to be seen as having limitations in participation.

Barriers that used to exist are no more. The same applies to the poor and the well-to-do, since education is accessible to all, irrespective of economic status. The notion that people who are blind or visually impaired persons must always lead a beggar's life is almost history, due to the fruits of education. Most of our graduates hold reasonable positions of service where they can earn a living, instead of resorting to the streets to look for survival. Their future is getting brighter every day.

In conclusion, I wish to pay great tribute to all our dear students, parents, guardians, and teachers, both current and past, for the good working relationships we enjoy under such circumstances. Although the roots of the process may be bitter, its fruits are very sweet. May our relationships flourish.

We should always be aware that beginning anything is not always easy but once the will is there things move on smoothly and ambitions can always be achieved. Nothing will always be impossible for as long as there is cooperation among the stake holders.

Good luck to all of us.

Zero Exclusion / Inclusion with Responsibility: Education for Students of Fragile Health and Multiple Disabilities

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Who are medically fragile children? The American Federation of Teachers (2009) defines them as:

... [S]tudents who require complex health procedures, special therapy or specialized medical equipment/supplies to enhance or sustain their lives during the school day. Because each child's condition is unique, his or her educational program must be determined on a case-by-case basis. (p.1)

We will use this definition throughout this article.

What are the educational rights of the Medically Fragile Child? The International Convention on the Rights of Persons with Disabilities states that:

“States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning” (Art. 24: Education, p. 18-19).

This Convention was signed on the 30th of March of 2007, with the participation of 191 nations, including the majority of Latin American and Caribbean countries.

This U.N. Convention is a guiding document for international organisations, establishing a new era in serving the diverse population of people with disabilities. The U.N.'s World Health Organization (WHO) invites us to reflect upon the information in the World Report on Disability, stating that “In the years ahead, disability will be an even greater concern because its prevalence is on the rise.” The Report shows that this increase is due both to the impact of acquired chronic diseases as well as congenital health conditions (WHO, 2011, p.5).

In the Incheon Declaration (Republic of Korea, 2015), the United Nations Educational, Scientific and Cultural Organization (UNESCO) reaffirms the Convention on the Rights of Persons with Disabilities. Further, UNESCO prioritises inclusion and equity in the World Education Forum 2015, especially for “... giving everyone an equal opportunity, and leaving no one behind ... the need for increased efforts especially aimed at reaching those marginalized or in vulnerable situations.” (UNESCO 2015, p.4)

These documents set a legal framework for the educational policies and practices that recognise the variety of challenges faced by people with fragile health, particularly those with multiple disabilities. Within this context, and beginning with this work, we focus on the

assistance of such students and their right to education, since they are frequently deprived of educational services.

Fragile Health, A Condition With Its Own Identity

Perkins International and its partner agencies have always worked to stay flexible in meeting the changing circumstances of students with multiple disabilities and fragile medical conditions. The nature and needs of this population changes with scientific and medical improvements. Following the guidelines of the U.N. Convention on the Rights of Persons with Disabilities, educational services must comply with the students' needs, interests, chronological age, family culture, and unique characteristics of the student, and make use of the temporary or permanent support that the student may need for a quality education.

In order to better understand the situation in Latin American, Perkins International and Fundación ONCE América Latina conducted the Latin American Permanent Survey on Services for Persons with Disabilities in 2014. We found that 68% of the 50 institutions surveyed provide services to 600 people with fragile health in Latin America. Of these institutions, the majority (46%) assist between 1 and 10 people with this condition; 16% between 11 and 30; and 6% more than 30 people. The purpose of this survey was to understand the reality experienced by people with this condition, and adjust the training needs of each work team and the educational services they provide.

Reinforcing the indicators from this survey are the authors' on-site observations. We see directly how this population group is overlooked, segregated, and neglected by

educational programmes and services. These students are offered proposals with reduced timetables and inadequate support.

It is a fact that this population of children and teenagers of fragile health with multiple disabilities is present in schools. It is also true that the work teams that deal with this situation too often lack the skills, materials, and personnel necessary to guarantee their student's rights. As a result the students and their families are left with no solution.

Without healthcare workers as members of the educational team, as well as a teacher who has all the knowledge necessary to work with this population, it is impossible to meet the medically fragile students' needs. It is of major importance to promote the cooperation between health and education to increase the learning opportunities, which are now reduced or nonexistent. This reality highlights the importance of professional training in the fields of education and medicine. Families must also understand their legal rights and responsibilities in order to work collaboratively as team members in support of their children.

In medical science, in order to achieve health education it is crucial to acknowledge the importance of family participation. Many of the habits and customs that are learned within the family are continued by people throughout their life. This is why the collaborative work between healthcare workers, teaching staff, and members of the family is so important.

The presence of students with fragile health at school involves responsibilities for all the members of the school staff: teachers, administrators, nurses, and other professionals. They each play crucial roles, and good training supports the physician/nurse when delegating

responsibilities, as well as assuring a safe and healthy learning environment.

Inclusive education with "responsibility" requires that governments adhere to certain principles that are crucial for a success. This is necessary to deliver quality services to all students, especially when the vulnerability is higher, as in the case of students of fragile health with multiple disabilities.

Hamre-Nietupski (1999) clarifies the requirements of high-quality inclusive education:

- Shared vision among administrators, professionals, parents, and community members about how to identify the needs of the student, how to satisfy them, and how to continue in the future.
- Administrative commitment and support from the government authorities, as well as the school principal where the service is provided. The government and school must guarantee the availability of the permanent and temporary supports, both material and human, that the student needs in the family, school, and community environments.
- Time for communication and cooperation between staff members and the family, in support of structured planning, consultation, and counseling.
- The state must also facilitate and support the permanent training and education of the staff members that will participate in the inclusion process of these students.

Further, a successful inclusive education programme for students with fragile health and multiple disabilities must include:

- Cooperation and collaboration between health services and educational centers;

- Transition from the early education services to the school services;
- Assessments that recognise the strengths and weaknesses of the student. They must be carried out by the whole team, including the family;
- A curriculum and programmes personalised to meet the needs of the student;
- A student-teacher-health professional ratio that supports the student's participation in the whole school day;
- The integration of what is learned at school into the home and community environments, and vice versa.

We must guarantee to the student with multiple disabilities and fragile health the opportunity to have a life as happy and fulfilling life as any other human being.

LOOKING AT THE FUTURE

When looking at the future, we must continue with actions and immediate structural changes in the educational programmes for people of fragile health with multiple disabilities. There is so much yet to be done to provide quality services in different parts of Latin America and the Caribbean. We still haven't included everybody in our education systems.

This vision can only be achieved if we align our vision and the law. This is why it is of major importance to continue the cooperative work with governmental authorities in order to carry out the necessary legal modifications.

These changes require teamwork with the family, professionals in the field of education and medicine, and the community in general. The child of fragile health with multiple disabilities should be the center of attention. We should work together to generate a change

in attitude, sharing of knowledge, and the training of medical and educational personnel, with the purpose of achieving the total inclusion of this population in society.

Both education and health are very important agents of change. This change cannot be achieved on its own. It requires the political support and commitment of our countries. Let's be part of this educational change so that all kids and teenagers of fragile health with multiple disabilities can have access to quality education!

Ignacio lives in the south of Latin America. In his 12 years of life he has fought difficult battles because of his health condition. His preterm birth affected his motor functions and his cognitive and physiological abilities. In his first years he lived far away from educational services, and spent many hours at the hospital. It required much time and paperwork to obtain an appropriate wheelchair. Because of his neurological instability, his family decided that it was better and safer for him to stay at home. Two years ago he started to attend a

therapeutic educational center, and this had a great impact on his life and his family's. Ignacio has developed communicative functions, allowing others to better understand his needs. His waking hours were extended and he enjoyed his educational improvement by means of a proposal written for him.

His education was interrupted by a hip luxation and surgery, but this time he and his family were aware of what he was losing by not attending school. The educational center had to rewrite Ignacio's proposal because the recovery process was slow and he would be learning at home for an entire school year. Ignacio's teacher learned how to work with her student while he was wearing a plaster cast from hip to toe. The physical therapist, who is member of Ignacio's health team, taught his mother some strategies for rehabilitation avoiding pressure sores. By working as a team, sharing knowledge and dreams, Ignacio's family, health professional, and teacher guaranteed his right to education.

Ignacio from Asociación Civil Identidades para Personas con Discapacidad Múltiple (ACIPDIM) Rio IV, Córdoba, Argentina

