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Partnerships in Early Intervention



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ICEVI

The International Council for Education of People with Visual Impairment

PRINCIPAL OFFICERS

PRESIDENT
Lord Low of Dalston
Royal National Institute of Blind People
105 Judd Street, London WC1H 9NE
UNITED KINGDOM
colin.low@rnib.org.uk

FIRST VICE PRESIDENT
Lucia Piccione
Giraudo 4225, Manz 8 Lte 23
Tejas del Sur, 5016 Córdoba
ARGENTINA
lpiccione1@gmail.com

SECOND VICE PRESIDENT
Frances Gentle
The Renwick Centre
Royal Institute for Deaf and Blind Children
Private Bag 29
Parramatta, NSW 2124
AUSTRALIA
frances.gentle@ridbc.org.au

PRINCIPAL OFFICER
Praveena Sukhraj
42 Windswawel Street,
Monument Park Extension 4,
Pretoria 0181,
SOUTH AFRICA
psukhraj@justice.gov.za

TREASURER
Nandini Rawal
Blind People's Association
132 Ft. Ring Road
Vastrapur
Ahmedabad 380 015
INDIA
bpaiceviad1@bsnl.in

PRESIDENT EMERITUS
Lawrence F. Campbell
1, Center Street,
Rockland, Maine 04841
USA
larry.icevi@gmail.com

REGIONAL CHAIRPERSONS

AFRICA
Tigabu Gebremedhin
CBM Country Office Ethiopia
P.O.Box 694, Addis Ababa
ETHIOPIA
tigabucbr@gmail.com

EAST ASIA
Suwimon Udompiriyasak
Faculty of Education
Suan Dusit Rajabhat University
295 Ratchasima Road
Dusit Dist., Bangkok 10300
THAILAND
suwimonu@gmail.com

EUROPE
Panagiota (Betty) Leotsakou
Ministry of Education
K.D.A.Y of Athens
12 Ioannou Kotsou Street
Glyka Nera 15354, Athens
GREECE
bl@icevi-europe.org

LATIN AMERICA
María Cristina Sanz
avda. 13 n 1207, flor 9 dpto. A
(1900) LA PLATA
ARGENTINA
latinoamericaicevi@gmail.com

NORTH AMERICA / CARIBBEAN
Kay Alicyn Ferrell
Professor of Special Education
University of Northern Colorado
Campus Box 146
501, 20th Street
Greeley, CO 80639
USA
kay.ferrell@unco.edu

PACIFIC
Ben Clare
Project Manager
Pacific Islands activities
Aspen Medical Foundation
PO Box 231
Deakin West ACT 2601
AUSTRALIA
bwclare@gmail.com

WEST ASIA
Bhushan Punani
Blind People's Association
132 Ft. Ring Road
Vastrapur
Ahmedabad 380 015
INDIA
blinabad1@bsnl.in

FOUNDING ORGANISATIONS

American Foundation for the Blind
Scott Truax
2 Penn Plaza, Suite 1102
New York, NY 10121
USA
struax@afb.net

Perkins School for the Blind
Dave Power
175 North Beacon Street
Watertown, MA 02472
USA
dave.power@perkins.org

Royal National Institute of Blind People
Lord Low of Dalston
105 Judd Street
London WC1H 9NE
UNITED KINGDOM
colin.low@rnib.org.uk

INTERNATIONAL NON-GOVERNMENTAL ORGANISATIONS

Deafblind International
Bernadette M. Kappen
999, Pelham Parkway Bronx
New York 10469
USA
bkappen@nyise.org

World Blind Union
Penny Hartin
1929 Bayview Avenue
Toronto, Ontario M4G3E8
CANADA
penny.hartin@wbu.ngo

International Agency for the Prevention of Blindness
Peter Ackland
London School of Hygiene & Tropical Medicine,
Keppel Street,
London WC1E 7HT
UNITED KINGDOM
packland@iapb.org

Visit us at:
www.icevi.org

INTERNATIONAL PARTNER MEMBERS

CBM
Lars Bosselmann
CBM EU Liaison Office (EU LO)
Third Floor, Rue Montoyer 39,
1000 Brussels, BELGIUM
lars.bosselmann@cbm.org

Light for the World
Nafisa Baboo
26 Niederhofstrasse
A11-20 Vienna, AUSTRIA
n.baboo@light-for-the-world.org

Norwegian Association of the Blind and Partially Sighted (NABPS)
Terje Iversen
P.O. Box 5900, Majorstua0308
Oslo, NORWAY
terje.iversen@blindeforbundet.no

Organización Nacional de Ciegos Españoles
Ana Peláez
C/ Almansa, 66, 28039
Madrid, SPAIN
apn@once.es

Perkins School for the Blind
Dave Power
175 North Beacon Street
Watertown, MA 02472, USA
dave.power@perkins.org

Royal Institute for Deaf and Blind Children
Frances Gentle
Private Bag 29, Parramatta,
NSW 2124, AUSTRALIA
frances.gentle@ridbc.org.au

Royal National Institute of Blind People
Kevin Carey
105 Judd Street, London WC1H 9NE
UNITED KINGDOM
Kevin.Carey@rnib.org.uk

Sightsavers
Andrew Griffiths
35 Perrymount Road
Haywards Heath
West Sussex RH16 3BW
UNITED KINGDOM
agriffiths@sightsavers.org

Royal Dutch Visio
Marten de Bruine
Amersfoortsestraatweg 180
1272 RR Houses
THE NETHERLANDS
martendebruine@visio.org

Chief Executive Officer
Mani, M.N.G.
5030, 3rd Floor, Sreevatsa Centre,
G.N. Mills PO, Coimbatore - 641 029
Tamil Nadu, INDIA
sgicevi@vsnl.net

Editor

Marianne Riggio
Director
Educational Leadership Program and International Campus Related Training
Perkins International
175 North Beacon Street
Watertown, MA 02472
USA

Associate Editor

M.N.G. Mani
CEO, ICEVI

Editorial Committee

Marianne Riggio
Lord Low of Dalston
M.N.G. Mani

Designing and Printing

ICEVI Secretariat
5030, 3rd Floor
Sreevatsa Centre
Mettupalayam Road
G.N. Mills Post
Coimbatore - 641 029
Tamil Nadu, INDIA

Telefax : 91-422-2648104
e-mail : sgicevi@vsnl.net

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Our International Partners

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Message from The President



This is my last message in the Educator as President of ICEVI - a new slate of Principal Officers will be elected at the General Assembly in Orlando in just over two weeks' time as I write.

The last Quadrennium has seen good progress, though much work is still ongoing. Our Global Campaign on Education for All Children with Visual Impairment (EFA-VI), run in conjunction with the World Blind Union (WBU), is gathering pace with new enrolments of children in excess of 110,000. During the Quadrennium we shifted our focus more towards advocacy and started working with broader organisations in the fields of education and disability to expand the campaign to now some 30 participating countries. Thus with the World Blind Union and the International Agency for the Prevention of Blindness, our partners in the loose-knit coalition the Vision Alliance, we participated in many global events with organisations such as the International Disability and Development Consortium, the Accessible Books Consortium and the Global Campaign for Education. The campaign was re-launched in Kampala, Uganda, in October 2015 in conjunction with the IDP Africa Forum, and was given a tremendous boost by a supportive message from Gordon Brown, former UK Prime Minister and UN Secretary-General's Special Envoy for Global Education, which focused particularly on the role of technology in enabling the inclusion of visually impaired children in the developing world in the same school as their sighted peers. It is gratifying too that earlier this year the Campaign was recognised as one of 86 innovative practices by the Zero Project in Vienna.

Our higher education project which is being implemented in Cambodia, Indonesia, Laos, Myanmar, the Philippines and Vietnam with the support of the Nippon Foundation has benefited 2142 students, who are now emerging as young leaders of the visually impaired and act as an inspiration to parents to send their visually impaired children to school. Other achievements during the Quadrennium can be seen in our Quadrennial Report 2012-16 which is available on our website www.icevi.org.

In an effort to strengthen our regions, we proposed to register them as distinct legal entities under the ICEVI umbrella, but the process proved more challenging than we had envisaged. The Latin America region has registered locally, but the other regions are still on the journey which will have to be completed in the new Quadrennium. We plan to undertake a strategic review in early 2017 to revisit our vision, mission and goals to ensure they are relevant to today's circumstances, and this may also suggest ways of strengthening the regions.

I should like to pay tribute to the work that Marianne Riggio of Perkins is doing as the new Editor of The Educator. We envisage a series of themed ICEVI publications based on the rich store of material to be found in the annals of The Educator over the years.

I should like to thank our International Partners for the major contribution they make to the work of ICEVI, and the Principal Officers and Executive Committee for all their support during the Quadrennium.

I wish ICEVI participants a successful General Assembly and greatly look forward to meet many of you in Orlando,

C. M. Low

Colin Low
President, ICEVI

Message from The Editor



Dear readers,

I am very pleased to introduce the latest edition of The Educator. As we received this wealth of very worthy articles, I was once again very heartened to think about how are field has grown and the great steps that have been taken toward assuring all children who are blind, visually impaired or deafblind receive the access to education that they deserve. Not too many years ago, there were only a small handful of programs serving infants and preschool children who are blind and visually impaired. In this issue, we are once again, seeing articles from every corner of the globe.

The theme is Partnershiphs in Early Intervention. We have many examples of strong partnerships among professionals, government agencies and most importantly, families. Several are reflections about what made these collaborations work. Some offer guidance in teaching and some share insightful research, others represent successful program models. Indeed, there is something for everyone.

Looking ahead to the January 2017 issue, we have selected as the theme *Transition to Adult Life.* As a new generation of children prepare to leave, or have already left, school a major challenge is in assuring that they live happy and productive lives. We will look forward to learning about the many innovative models that are in place that provide training and support that is needed for people who are blind, visually impaired or deafblind, that promote work or meaningful activity, social inclusion and happy family lives.

I hope you will enjoy reading on.

With appreciation and best wishes,

Marianne Riggio

Marianne Riggio
Editor

ICEVI QUADRENNIUM 2012-16

The ICEVI Quadrennium 2012-2016 comes to an end with the conduct of the ICEVI General Assembly on the 25th August 2016 in conjunction with the World Blind Union (WBU) – ICEVI Joint Assemblies in Orlando. ICEVI has published an extensive Quadrennial Report highlighting the key achievements of the ICEVI regions and the full publication is available on ICEVI's website www.icevi.org . The July 2016 issue of The Educator includes a summary of this Report.



The 2012-16 Quadrennium was marked by synergy and networking between the WBU and ICEVI. The collaboration symbolises a new beginning of combined strength in confronting global challenges in promoting the education of children with visual impairment. Following the successful conduct of the first ever WBU-ICEVI joint assemblies in Bangkok in 2012, there was an overwhelming response from both constituencies to continue the joint initiative. This has resulted in the second joint assemblies in Orlando in 2016.

EFA-VI Global Campaign highlights:

Recognising the success of the consolidation phase of the Global campaign on Education For All Children with Visual Impairment (EFA-VI) till 2014 which facilitated school enrolment of nearly 110,000 children with visual impairment, the ICEVI EXCO suggested expanding the campaign by involving more mainstream players and also switching our focus on more awareness and networking instead of facilitating direct delivery of services. During the 2012-16 Quadrennium, ICEVI expanded its capacity building programmes to include such audiences as policy makers, general public, teacher educators and parents. ICEVI has organised or supported a record number of 659 programmes in all seven regions of ICEVI. These programmes have helped in the training of over 60,000 teachers and 60,000 parents and general public.

ICEVI acknowledges that the additional enrolment of children with visual impairment was possible because of the proactive policies of Governments and the work of our International partners and local voluntary organisations in many regions. ICEVI is convinced that the role it has played as a "catalyst" to promote education worldwide is yielding the desired results and it will continue to do so in the future to ensure that no child with visual impairment is "left behind".



Lord Low receiving the award from
Mr. Martin Essl, Founder, Essl Foundation

The Zero Project is an initiative of the Essl Foundation, and focuses on the rights of persons with disabilities globally. The Zero Project recognised 86 innovative practices in February 2016 and the EFA-VI Global Campaign was one among them.

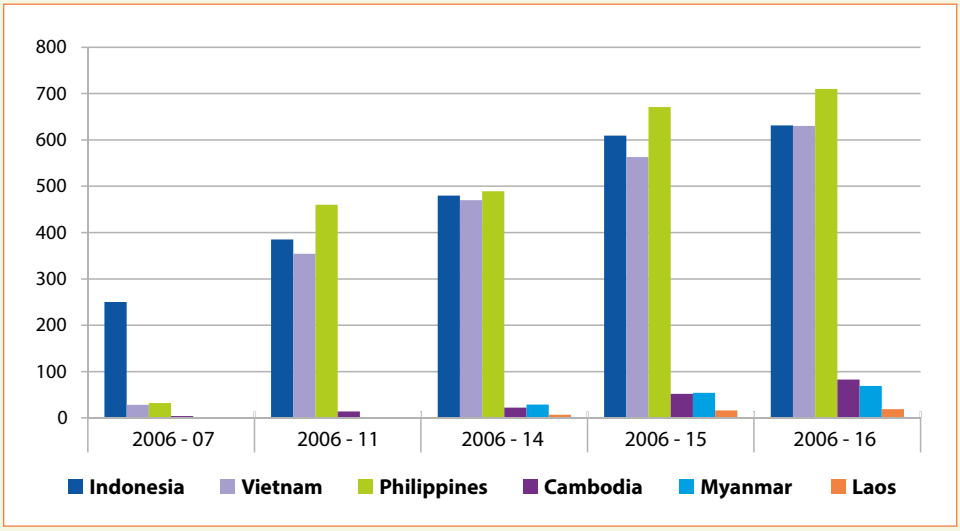
ICEVI's collaboration with the Global Campaign for Education (GCE) has brought us in contact with many National Coalitions on Education, and as a result, our regions have used these platforms to advocate for the education of children with visual impairment. ICEVI actively celebrated the Global Action Week (GAW) in many of its regions. The activities brought many mainstream organisations and ICEVI face-to-face to initiate measures to hasten the enrolment of children with visual impairment.



Global Action Week and Day of African Child Sports event in Uganda

Steady Growth of the Higher Education Project

The ICEVI Higher Education project supported by The Nippon Foundation commenced in Indonesia in 2006-2007. The project was extended to the Philippines and Vietnam in 2008, Cambodia in 2010, Myanmar in 2013, and to Lao PDR in 2014. The broad objective of the project was to promote inclusive make higher education institutions and to develop the skills and performance of students with visual impairment in each of the project countries, by providing them with technology training. The project has resulted in significant increases in access to university education in the project countries, with 177 additional students benefitting from the Higher Education programme during 2015-16. Since commencement of the project in 2006-2007, a total of 2,142 students with visual impairment have been beneficiaries of the project.



From 2012-2013 onwards, the focus on employment became an integral part of the project, with the project partners focusing on preparation for employment, technological applications, and advocacy towards inclusive universities. The training initiatives of all project partners on "soft

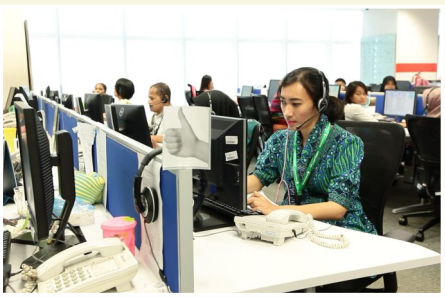
skills" and employment preparation were offered to the students with visual impairment while they were undergoing higher education courses. This resulted in the generation of gainful employment for a number of the students. Vietnam has provided job placements for 27 persons, Cambodia has placed 38 persons in employment, of whom 11 are concurrently studying and working part time. The Philippines has placed 13 persons with visual impairment in employment sectors, and Indonesia has facilitated employment opportunities for 39 persons.



Employment Counselling in Vietnam



Employment in Radio Station, Cambodia



Precilia Oktaviana working at the Call Centre, Indonesia



The Nippon Foundation was given a special award at the Regional Conference of ICEVI East Asia region held at Bali, Indonesia from 28 September to 1 October 2015. The award was presented to The Nippon Foundation in grateful recognition of their support and partnership in expanding educational access and full inclusion for persons who are blind or have low vision in the East Asia Region. Mr. Shuichi Ohno, Executive Director of the Nippon Foundation received the award and delivered a special address.

Regional Development

Regional development is one of the thrust areas of ICEVI and the Executive Committee has encouraged the ICEVI Regional Committees to consider the possibility of registering their regions in order to become legal entities. Until 2015, the Europe and Pacific regions were the only ICEVI regions registered as legal entities. While discussions are underway in other regions, the Latin America region took the lead and registered the region as a legal body in Uruguay on 27th April 2016.

Regional Conferences

Regional Conferences are an integral part of the ICEVI's networking and advocacy work. These conferences bring large numbers of parents and the professionals from the regions to discuss region specific issues as well as priorities. During the Quadrennium the following regional conferences were conducted:



ICEVI West Asia Regional Conference, New Delhi, India, 2013



Colin Low inaugurating the ICEVI West Asia-ABU Conference

S.No.	Regional Conferences	Venue	Date
1	ICEVI and Deaf Blind International (DbI) Joint West Asia Regional Conference	Ahmedabad, India	5-7 April 2013
2	ICEVI 8th European Conference on Education and Rehabilitation of People with Visual Impairment	Istanbul, Turkey	30 June to 5 July 2013
3	ICEVI Sixth International Conference for East European Countries	Chernigiv, Ukraine	10-12 October 2013
4	South Pacific Educators in Vision Impairment (SPEVI) Biennial Conference	Auckland, New Zealand	13-18 January 2013
5	Pacific EFA-VI Forum and SPEVI Biennial Conference	Melbourne Australia	9-15 January 2015
6	The International Conference on Enabling Access for Persons with Visual Impairment (ICEAPVI - 2015)	Athens, Greece	12-14 February 2015
7	ICEVI East Asia Regional Conference	Bali, Indonesia	28 Sept.-1 Oct. 2015
8	ICEVI West Asia - Asian Blind Union Regional Conference	Ahmedabad, India	13 March 2016

Global Networking



Asia-Pacific Regional Educational Conference, Bangkok

ICEVI enjoys consultative status with the United Nations Economic and Social Council (UNECOSOC) and UNESCO, and participates in various policy formulation meetings of the UN agencies. At the global level of policy formulation and advocacy, ICEVI works with the Global Partnership on Children with Disabilities (GPCwD), Global Campaign for Education (GCE), Southeast Asian Ministers of Education Organisation Regional Centre for Special Education (SEAMEO-SEN), World Blind Union (WBU) and International Disability and Development Consortium (IDDC).

Vision Alliance



The Vision Alliance is an initiative of ICEVI, WBU and the International Agency for the Prevention of Blindness (IAPB). The aim of the Alliance is to create greater synergy and collaboration between the three organizations at global, regional and national levels in order to improve services and programs of each organization. The Vision Alliance meetings were organised on a number of occasions during the quadrennium, including a Vision Alliance exhibition stand at the Lions Convention in Toronto on 3-8 July 2014 which attracted many local Lions members.

Activating Parents' Movement



ICEVI is a strong supporter of the Parents' Movement in the area of Visual Impairment. Representatives of Parents' Organisations are regularly invited to ICEVI executive committee meetings and to special events. The Parent Advocates for Visually Impaired Children (PAVIC) in the Philippines will be organising its next conference in May 2017 where an initiative to expand the parents movement to the entire East Asia region is likely to be discussed. ICEVI will support this conference in 2017 and will also take an active role in expanding the Parents' movement in the East Asia region and beyond.

Math Project – A much awaited Initiative

ICEVI, with the support of The Nippon Foundation, has initiated a project to develop Mathematics video packages for facilitating teachers to effectively teach mathematics to children with visual impairment. The core group of this initiative comprises representatives of ICEVI, Texas School for the Blind and the Visually Impaired (TSBVI), Perkins School for the Blind, and the Overbrook School for the Blind. The group has met in Austin, Texas twice and developed a concept note for the pilot phase of development. An academic team consisting of members with expertise in teaching mathematics to visually impaired children has been formed and their preliminary work will commence early in the next ICEVI quadrennium. The project team plans to prepare video lessons for teaching about 200 mathematical concepts covering the K-12 curriculum during the project period 2016-19.

ICEVI Awards

ICEVI recognises individuals who have made a significant contribution to the field of education of children with visual impairment and also to the activities of ICEVI. The Awards Committee for the 2012-16 quadrennium, chaired by Lucia Piccione, 1st Vice President of ICEVI, has reviewed the nominations submitted by the regional chairs and the principal officers and selected the following people who will be presented with awards and citations during the ICEVI General Assembly in Orlando in August 2016.

- **Harry Svensson,** Sweden, who served as the Vice-President of ICEVI and served as the editor of ICEVI's official magazine The Educator from January 2007 issue to January 2011 issue.
- **Nandini Rawal,** India, who has served as the ICEVI Secretary (1997-2006) and Treasurer (2006-present), and has significantly contributed to the accounting procedures of the organisation. Nandini also serves as the Executive Director of the Blind Peoples' Association, Ahmedabad, India.
- **Phalla Neang,** who has conducted many ICEVI capacity building programmes and was adjudged as one of the top 10 inspiring teachers of the world as per a global voting initiative.
- **Rima Canawati,** who has served as the Deputy Regional Chairperson of the ICEVI West Asia region and has contributed significantly to coordination of work in the region. Rima has also been instrumental in fostering a partnership between ICEVI, CBM and the Government in Palestine.

EXCO Meetings

The Executive Committee, the highest policy making body of ICEVI, consists of 5 Principal Officers, 3 Founding Members, 3 Members of Umbrella Organisations and 9 International Partners. The EXCO meets at least once a year to review the work and also to plan its future work. The Executive Committee of ICEVI met five times during the quadrennium 2012-16.

EXCO Meetings	Venue	Date
Meeting 1	Bangkok, Thailand	18 November 2012
Meeting 2	London, UK	09-10 February 2013
Meeting 3	Vienna, Austria	14-15 November 2013
Meeting 4	London, UK	08-09 April 2015
Meeting 5	Kampala, Uganda	03-04 October 2015

Strategic Review to define the future road map

The last fully-fledged Strategic Plan of ICEVI was developed in 2002, with subsequent reviews and modifications of the strategies wherever necessary. The ICEVI EXCO believes that the role of ICEVI as a "convening organisation" in the future will have ramifications for its activities, including its future partnerships and networking, and advocacy and research activities. The ICEVI EXCO is planning to carry out an extensive Strategic Review in early 2017. The review will include revisiting ICEVI's Vision, Mission, Goals, and international and regional structures and activities.

Other Key Events

Besides ICEVI EXCO and regional meetings, ICEVI took part in the following key meetings during the quadrennium.

S.No.	Meeting/Conferences	Venue	Date
1	ICEVI at the High Level Meeting of UN	New York, USA	23 September 2013
2	ICEVI in Global Partnership on Children with Disabilities (GPCwD) Meet	New York, USA	24 September 2013
3	ICEVI and WBU submission - Joint Response to the CRPD Committee's Draft General Comment no. 4 Article 24, The Right to Inclusive Education		8 January 2014
4	ICEVI at National Inclusive Education Programme Launching Ceremony	Ramallah, Palestine	29 January 2014
5	ICEVI in the IDDC Task Group Meeting	Brussels, Belgium	February 2014
6	ICEVI Meeting with Parents Advocates for Visually Impaired Children (PAVIC)	Manila, Philippines	22 April 2014
7	ICEVI supported PAVICs 4th National Parents Congress	Manila, Philippines	9-11 May 2014
8	ICEVI in CCNGO-EFA Meet	Santiago, Chile	21-23 May 2014
9	ICEVI in IDDC Inclusive Education Task Group Meeting	UK	May 2014
10	ICEVI in IDPP Advisory Board	Kuala Lumpur, Malaysia	10 August 2014
11	ICEVI in Inclusive Education Multi Stakeholder Roundtable	Kuala Lumpur, Malaysia	12 August 2014
12	ICEVI in WBU–Asia Pacific Mid-Term Regional General Assembly	Hong Kong, China	21-24 November 2014
13	ICEVI at the UNCRPD Education Discussions	Geneva, Switzerland	15 April 2015

Scope for Global Networking

The consolidation phase of ICEVI commenced in 2002, and included preparation of a thorough Strategic Plan, invitations extended to organisations to become International Partner Members and to serve on its EXCO, and establishment of a fulltime Secretariat. The year 2002 was significant for ICEVI as it celebrated its golden jubilee. The 2002 strategic plan listed the following six goals for the organisation.

- To ensure access and full participation in education for all visually impaired children and youth by 2015.
- To promote and assist in building of local capacity to develop curricula, to provide training and to identify and provide equipment and materials to children and youth with visual impairments and their parents, teachers and others in their communities.
- To collaborate with and make use of networks to ensure that substantially more visually impaired children and youth receive quality and comprehensive education.
- To ensure that ICEVI initiatives are based upon current evidence of best practice.
- To provide information on ICEVI and its services through all possible and appropriate media to all target groups.
- To build a strong base for ICEVI.

The achievements of ICEVI over the past decade are noteworthy, and include the launch of the EFA-VI Global campaign, advocacy with global bodies, networking with international partners and umbrella organisations, research and development activities, preparation of concept and position papers, regional development activities, higher education programmes, and employment. ICEVI has compiled a significant body of evidence and models that have the potential to make education for all children with visual impairment a reality. ICEVI wishes to increase its advocacy and networking roles in the future, and to work with mainstream organisations and global bodies to influence education polices and practices.

ICEVI has served as a "Convening Organisation" and catalyst, and has the potential to effectively contribute to global networking in the years to come. The ICEVI Strategic View planned for early 2017 offers the opportunity to establish a broad framework for the future of ICEVI.

Fortieth Anniversary of Services for Children with Visual Impairments in Hungary

Zsuzsanna Dr. Földiné Angyalossy, Sára Dobrik-Lupták, Éva Lantos, Csilla Liptai, Ágnes Borhy, Tímea Sinka-Fábri, Laura Dobrocsi, and Krisztina Pál-Bártfai
National Board of Assessment of Visually Impaired Children, Early Interventional and Trainer Care Service, Hungary
info@latasvizsgalo.hu

Introduction

Hungary's National Board of Assessment of Visually Impaired Children, Early Interventional and Trainer Care Service was established in 1976. We celebrated our 40th anniversary this year on 25th April, with a big congress. Our institute is situated in an attractive green area of Budapest's city center, which is easy to reach from both the city and the countryside. We are in a new modern building, which we moved into in 2005.

The scope of our work is national and consists of three parts:

- Early intervention (0 -5 years old);
- Special examination of visually impaired children (0-17);
- Education services (for university students).

Numbers and Our Work

Children are sent to us by doctors, health visitors, and eye-specialists. Sometimes parents come to us after learning about us from other parents. Since the beginning of 2015, we have provided services to 85 children. 60 of the children were aged 0-3 years old, and 25 were 3-6 years old. About 45 of them have other disabilities in addition to visual impairment.

When children arrive, we provide psychological, visual, and special educational evaluations. We take all of these assessment tools into consideration:

- Developmental scales;
- Visual function assessment tools;
- Perceptual development tools;
- Psychomotor development scales;
- Observation of child;
- Parents' observations.

In our organisation we define visual impairment as visual acuity with two eyes under 30%, or a visual field of 20 degrees or less.

Intervention Programmes

Programme	Target Group	Professionals who develop it	Brief Description of the Programme	Place where it is developed
Complex one-to-one early intervention	0-6	Teachers for visually impaired children	Visual stimulation, intervention orientation and mobility, social interaction skills, self determination, family support, coordination	Home, Crèche, Kindergarten, Early Intervention Centre
Physiotherapy	0-6	Physiotherapist	Orientation and mobility, coordination, passive movement and active exercises	
PSMT Trainer	0-6	PSMT therapist	PSMT exercises	
Hydrotherapy	0-6	Hydrotherapist	Special exercises in water	Swimming pool

Schooling for Visually Impaired Children

Children aged 1-3 years go to crèche, and those with disabilities go to a special group within crèche. Children who need early intervention session or guidance can get these services in their crèche or in our institute.

Children between the ages of 3 and 6 go to kindergarten. Children who are visually impaired are included in the local kindergarten, with early intervention services from itinerant teachers from the School of Blind Children or the School of Visually Impaired Children, which serve the entire country.

While kindergartners who are blind or with multiple disabilities may also be included in their local kindergarten, many schools are not able to accommodate them. Therefore most of these students go to the Kindergarten of Blind Children.

We provide early intervention for children from ages 0-5. Children aged 5 and 6 years usually can get developmental education if we don't find a suitable institute.

School Support

In Hungary we have a School for Blind Children, two Schools for Visually Impaired Children, and a Catholic Primary School for Blind Children.

It is also possible for a blind or visually impaired child to go to a public school. In that case the child gets support at school by a network of itenerant teachers, who teach braille, orientation and mobility, use of the white cane, technology, daily living skills, etc. The schools where visually impaired children are enrolled have the following resources:

- Reduced teacher/pupil ratio;
- Specific training for professionals;
- Internal or external support teachers;
- Access to specific resources and materials;

Visits of from itinerant teachers for visually impaired students (once a week or month).

The Level of Support Given to Visually Impaired Children in Public Schools

Level of Support	Very Low	Low	Medium	High	Very High
Learning			x		
Socialisation				x	
Autonomy		x			
Endowment of specific resources		x			
Family care				x	
Support to the school where the child is enrolled					x

Support for Families of Visually Impaired Children

There are specific programmes for families of visually impaired children, including family days, family weekends, parent groups, banquets, and holiday and end-of-school-year celebrations. Mentor parents' network is an association of parents of visually impaired children in early intervention. Families' participation in these activities, and cooperation in their children's intervention programmes, is very

high. An opinion survey we administered tells us that the families' are very satisfied with the intervention services for their children.

We communicate with our students' families in a number of ways. We use Facebook, our website, and handouts. We also organise open days, and answer questions from parents of current and prospective students. When applying for services, families make special requests on the test application form and we follow up with them.

Professionals
We have a multi-disciplinary team for early intervention that can serve the needs of students who are visually impaired, blind, hearing impaired, or developmentally disabled. Our specialists include a physiotherapist, a PSMT trainer, a somato-pedagogue, a psychologist, an eye-specialist, and a hydrotherapist.

Training for professionals:
Our university offers specific training in general early intervention, early intervention for visual impairment, and early intervention for multiple disabilities. Our organisation cooperates in specific training programmes, e.g., PSMT, BLISS Foundation.

Relationships
Relationships are a very important part of our work. First of all we keep in close communication with the parents and with the families of our students. We visit the families, and when necessary, we deal with the children in their own homes. We involve the parents in the process, and welcome them to participate in our sessions. We advise them on how to interact with and play with the children, how to foster their development, and how to create the best environment. We support them in many other areas: finding other professionals, and finding special tools, beds, prams, pushchairs, and medical appliances.

We keep in contact with eye specialists, psychologists, physiotherapists, teachers in public schools and in kindergartens, feeding therapists, and health visitors. We are also in contact with neurologists, orthopedists, conductors, and psychologists in hospitals doing long-term follow-up with premature babies.

We participate in appropriate professional congresses and trainings. We share our experiences with pleasure with other colleagues, while remaining open to new information and new methods. We often make on-site visits to other professionals. We have recently arranged to visit a department of developmental neurology in a hospital. This year we also visited Immanuel Home Care for Multiple Disabled Children, and the Institute for Blind and Visually Impaired Adults.

Our institute is open, and we often have visitors – we welcome other professionals dealing with children, both from Hungary and from abroad. We also welcome teachers in training; they study and practice here, so we are in close contact with the university. We participate in the Erasmus programme, which trains foreign students to become early intervention specialists for children who are deaf or blind.

Legislation

Our country has legislation assuring the rights of children with disabilities, including social and school inclusion. Other rights are granted for people with disabilities:

- Travel support;
- Extra financial support for the family;
- Parking allowance;
- Accessibility of public institutions;
- Equality of access to information;
- Right to education.

Summary

We our proud to serve children with visual disabilities and their families. On the occasion of our 40th anniversary, we are committed to serving our nation for many more years.

Reference

European Survey about Early Intervention for Visually Impaired Children





Indonesia's First Baby Camp: "We met, shared, learned, and laughed together – it was fun, fun, fun!"

Weningsih
Educational Specialist / Perkins International, Asia/Pacific Program, Indonesia
Weningsih@Perkins.org

Ayundira is a 2.8-year-old girl who lives in Banjarmasin, a big city in the Indonesian portion of Borneo. This spring her parents flew with her to Bandung in West Java to attend Perkins International's Baby Camp. They hoped to meet other parents like themselves, and learn how to train their daughter.

The previous few months, Ayundira's parents had been anxious and worried, realising her development lags behind other children of her age. Since Ayundira was diagnosed, they had been looking for information about her condition and services for her, but none were available. Fortunately, both parents are proficient users of internet resources. They found an Early Intervention Programme (EIP) in Jakarta, and were ultimately referred to Perkins International (PI) staff.

Lilih, a mother of 2.5 year-old Anin, had similar experiences. The family lives in Bogor, 60 km from the Indonesia's capital of Jakarta. Since her daughter was born, Lilih has known her daughter has a visual impairment, and that there is no treatment for it. She searched for information about raising a baby with visual impairment, but could find nothing. Like Ayundira's parents, Lilih is a skillful internet user, and eventually she found a new parent support group. Although it provided emotional support, Lilih still felt powerless and lacking in confidence. She took Anin to physical therapy sessions one in a while, but she did not see significant progress. When she learned about Baby Camp, she was eager to attend and meet other parents.
We hear from many families whose



children have visual impairments in Indonesia, and the challenges of Ayudira's and Anin's families are very common. They share the same problems: lack of information in the local language, scarcity of early intervention service providers, and geographical isolation. Indonesia has a population of nearly 250 million spread across more than 17,000 islands. Today there are only three early intervention programmes for young children with visual impairment in all of Indonesia, and very few pre-school programmes associated

with the schools for the blind. Getting services to the population is a huge problem.

In Indonesia, young children in every village attend playgroups, which are either privately run or run by the community. But, teachers are not trained or prepared to accommodate children with disabilities, and most are not enroled in these pre-school programmes.

Perkins International attempts to reach out to these children and connect them with early intervention programmes. Those who live in Bandung are fortunate because they can participate in an EIP run by Yayasan Penyantun Wiyata Guna (YPWG), highly supported by Perkins International. Although there was initially only one trained staff member in the programme, it made a huge difference to the families and children's future. In 2015, Yayasan Bhakti Luhur Bandung joined YPWG to serve young kids in the area, and the children and families come to the center twice a week.

However, it has been difficult to find organisations willing to provide these services in other areas. Therefore, we have had to innovate. PI initiated and is managing a parent online group for 59 families through WhatsApp, a mobile messaging app for smart phones. The families share strategies, discuss their experiences, and support each other. As the parents got to know each other, they realised that they needed to meet in person.

To bring the families together, Perkins International organised Indonesia's first Baby Camp for parents of children with visual impairment. Seventeen families came from cities and islands all over Indonesia. At the Camp, families met each other, met teachers, and learned how to create games, toys, and learning materials.

Five organisations were involved in the Baby Camp. Although each organisation has its own focus of work, they share a commitment to supporting families, and collaborated well. The organisations were:

- Sayap Ibu Banten, with orphanage and programme outreach;
- Bhakti Luhur Bandung, with school and CBR programme;
- Yayasan Penyantun Wiyata Guna with an early intervention programme;
- Helen Keller school, with Yogyakarta deafblind school;
- Balita Tunanetra, an online parent group.

The Baby Camp was held in Lembang, a small town close to Bandung, and spanned three days at the beginning of April 2016.



The families participated in activities for babies, parents, and teachers from morning to evening. We began with an introduction game, in which the parents wrote down

their expectation for the Camp, as well as their dreams for their children's future. At the Camp, teachers and parents of older children gave the families ideas and strategies to be implemented at home. Participants could choose from multiple



class offerings, such as gross motor development, visual stimulation, dress up, feeding preparation, toilet training, and transition into typical pre-school. This gave the parents the ability to select information that aligned with their needs and interests.

The parents learned about techniques for helping their children at home, had discussions on developing team work in their families, participated in role play and sensitivity activities, and learned how to cultivate positive beliefs about themselves and their children. By preparing simple snacks together, they had fun and experienced how to turn daily activities into "learning" opportunities for kids.

For the children, we created play corners with cheap and easily available materials. Children moved from corner to corner and explored different materials and games with their parents. Story boxes and tactual books were placed in story corners, and various hanging toys, boxes, and mats with toys were available in "little room" corners. We placed art and hanging pots near the walls to produce different sounds. These corners gave the parents ideas for stimulating their children's development with inexpensive materials. We also asked the parents to make a toy to bring home. Many of them made hanging toys, pre-cane/push toys, and toys to develop fine motor skill.

The Baby Camp was also for the parents. We wanted to help them release their stress and burdens. Too often, parents do not have time for themselves or for fun activities; some have even forgotten how to have fun since their children were born. We wanted them to laugh, do silly things and just have fun! We created activities to make them "feel happy and laugh".

We wanted to break down the wall between educators and parents, so we created activities to make them work as a team. We also wanted to strengthen the network of the organisations and teachers involved, to start sharing responsibility and vision. During the Camp, it was great to see how they supported each other and learned to work as a team. Things work better when we share a similar goal.

Parents who participated in the Camp found it easier to speak positively about their children. They also developed optimistic beliefs and confidence that will guide them in the future. They also identified some topics they need to learn more about and recognised that they need ongoing support.

At the camp, we saw parents working hard to implement their new ideas. Anita patiently waited, allowing her four-year-old son Gilby to put his musical instrument into its case with minimum support. She had learned the importance of letting him do it himself, even though it took longer. Another child, two-year-old Thalita, enjoyed the hanging pots, which produce a loud sound. She kept looking to her mother to guide her movements, as she has always done. But Thalita's mom now merely directed her to the room's landmarks, allowing her to orient herself. Lilih, mother of Anin, said, "I learned lots of new ideas on handling my daughter which I did not get from anywhere [else]."

The parents who attended the Baby Camp reached out to other parents in the WhatsApp support group, sharing their new knowledge and experiences. It has stimulated the interest of other parents and fostered discussions. The number of parents attending the Early Intervention Programme at YPWG has increased, and the families who live in Jakarta and neighboring cities have started in-person monthly meetings.

This year, YPWG recorded 217 children from 0-6 years with visual impairments. They were referred from Cicendo Eye Hospital in Bandung, the largest such hospital in the country. Almost 70% of new cases in these last two years are retinopathy of prematurity. We don't have a record of the numbers of babies who have been diagnosed in other hospitals, as there is no referral system, but we believe the number is increasing.

Indonesia needs multiple approaches and many innovations to identify children with visual impairment, serve them, and empower their families. This work calls for the involvement of multiple stakeholders, including the government. We have learned that team work is the best approach for providing quality early intervention, and are eager to reach as many families as possible by offering Baby Camp regularly and in different cities in Indonesia.

Lilih : She has high expectation to learn information and skills to work with her daughter at home. It was hard and felt guilty, such an irony as herself is a primary school teacher but has less competency to help her own child.





Early Intervention for Low Vision Children: The Important Partnership with Families

Ana Lucia Pascali Rago, Physiotherapist, Psychoeducator, and
Team Coordinator / Santa Casa Hospital, Low Vision Section, São Paulo, Brazil
analurago@hotmail.com

Introduction

The Low Vision Service staff of São Paulo's Santa Casa Hospital has worked for many years in early intervention services. We have come to realise the great importance of having the families involved in their children's programmes. More than that, we have learned to invite the families to become active members of the collaborative team, building a real and effective partnership. We give parents a place where they are listened to, where they can express their concerns and ask questions, share their fears, anxieties, and desires, and where they can support one another and find solutions. As we worked to create this partnership approach, we realised how much we can learn from each other, and how this learning could benefit us all, especially the child.

Partnership with Families / Sharing Experience

The child develops quickly in the first three years of life, especially in the first year. During this time, he/she learns and develops many functions and skills through a collaboration between the developing nervous system, and the stimulus offered by the environment. For full development, it is necessary for the child to interact with the environment, people, objects, and situations. It is necessary to play.

The learning brain needs to receive and integrate a great volume of information, coming from all the sensory channels. Vision is the most important channel because it is an instant way to capture information and to understand the environment.

Young children with cognitive, sensory, or motor disabilities have difficulty in interacting with and adapting their environment, especially if there are multiple disabilities. Babies with disabilities may be less aware of stimuli from the environment, or be less able to interpret and/or respond to them appropriately (Hari, 1988). Those with visual impairments or multiple disabilities tend to play less and explore the environment less. Further, their families often interact and stimulate them less, because they do not understand their ways of communication, movement, exploration, and interaction.

Many times parents feel frustrated because they cannot identify their infant's responses to their interaction attempts. The baby also feels frustrated because his or her reaction to the parents is not understood and not responded to. “In this situation, the infant's responses do not reinforce the caregiver's interaction and vice versa. Thus, begins a cycle of unfulfilled expectations and

unsatisfying interactions between the caregiver and the infant" (Chen, 1999, p. 6).

Because of the importance of early development, the focus of early intervention should be on bonding and communication for the child and the family. It is within this context that the child interacts, learns, and develops. So, the most used model of intervention, and most suggested in recent literature, is the family-centered philosophy. "Families are composed of the most significant people in infants' lives, and babies usually spend most of their time in the care of their families. It is through interactions with families that infants develop emotional ties, become social beings, and discover that their actions have meaning" (Chen, 1999, p. 7).

We begin our work with a family by inviting them to be part of the process. We make sure they understand that stimulation begins at home, during the family's daily routine and natural activities. This encourages the family to stimulate their child more spontaneously, and frees them from the feeling that interacting with their baby is a "job".

We find it very important to make sure families understand why they should follow our suggestions and instructions. When parents realise that we share their goals for their child, and understand how the early intervention programme benefits their child, it is much easier to work with them as partners.

To involve families more and more in this collaboration, we have been developing workshops for parents. We cover many subjects in the workshops, including the nature of visual impairment, its impact on a child's learning and development, and nervous system functions. We discuss the responses that parents may observe in their kids, how to adapt the home environment, and activities they can do together. We always speak in nonclinical language that is understandable for all.

In our workshops, we make sure that parents understand their child's behaviours, because understanding makes things easier. We encourage parents to share their feelings, doubts, frustrations, desires, and solutions. In these intimate settings, they can find common ground and help each other.





Mothers learning to get eye contact with their babies: learning the child's distance of response and the time they need to respond



Mothers sharing experiences in groups of parents with and without children

We also have meetings that bring all the parents and children together. Here again, they can share ideas, solutions, activities, strategies for communication, and much more.

We provide home visits, which make families feel more confident about adapting activities of their daily routines and integrating their children into community places. During the early intervention work with the baby at the center, the parents are always with us, playing together and being part of the activity. This makes the activities much more pleasant to the family and to the baby. The families participate actively in setting the goals of the intervention programme, fostering self-confidence and confidence in the professional team.

Conclusion

We work with families in many different ways, with many different strategies. This brings them closer to the service, to the team, and especially to the child. It fosters a strong bond, based in reciprocal confidence and respect. Recognising and nurturing the strengths of the child and of the family empowers them and encourages them to know their child better each day. Perhaps most importantly, empowered and engages families realise that they have a fundamental role in the success of their child.

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Building Up Partnerships Between Parents and Professionals in the Early Years

Sheela Sinha, Helen Keller Institute for Deaf & Deafblind, India. e-mail : sheelasinha@gmail.com

The birth of a child with disabilities brings a series of challenges for the family. It necessitates a number of adjustments and redefines the roles and relationships of family members. This creates a need for partnership with professionals who can help the family members. Together they can build on the child's potentials and help him or her learn and grow in a joyful manner.

The parent-professional partnership will change meaning throughout the changing contexts and stages in a child's life. Although the core goal will always be "working together for the betterment of child and the family as well as society at large", the significance of various aspects of partnership may assume different magnitude. For example, in the early years, the partnership will emphasise emotions and medical and educational services. Later in the transition stage, the focus will be on advocacy, skill development, networking with prospective job providers, legal provisions, entrepreneurship, etc. Here we will analyse some of the factors that dominate in the early years, with the main focus on partnership between the parents/family and the professionals.

There are many elements to successful partnerships in the first few years of a child's life:

- The parents, family, and the professionals go through the pleasures and pains of the early years together. As the family realises that the child's growth and development will need special clinical and educational intervention for an extended period, they experiences the first pang of pain. They need maximum support in the form of assurance that they are not alone, and that there are people and agencies whom they can turn to for appropriate guidance. They need emotional and informational support to for their seemingly never-ending pursuit of the right services and getting answers about their child's growth and behaviour. They need help in organising the information and using those resources, all while facing the many responsibilities and demands of daily life.
- Family and professionals need to communicate constantly about the needs and preferences of the child. This includes the skills related to play and routine activities already acquired, and the ones which must be acquired in the near future. Parents are the best judge of their children's needs, emotions and expressions, but professionals are trained to evaluate these emotions and use them to help the family meet the child's learning and developmental needs. So both partners complement each other, but unless they have regular interactions, relevant aspects of the child's development may remain unattended.

- The child's educational plan calls for parents and professionals working together to decide which services are appropriate, and what aid, appliances, and technology shoud be used.
- The team shares the responsibilities for fostering the child's growth and development. The behaviours observed at home must be taken into account by the professionals, and the family must follow the programme created by the professionals. Together they must accommodate the home routine of the child and the entire family.
- Parents and professionals must communicate their concerns about and expectations for the growth and welfare of the child as well as the family.
- The partnership gives the parents a place for emotional catharsis with a patient and understanding listener. Many parents need a place where they can share their feelings and anxieties without encountering ridicule or hurtful comments. This trust also assures the professional that his or her suggestions and support are valued and respected.

Now let us look into a few objective steps which can lead to a healthy, fruitful and mutually satisfying partnership between the family and the professionals.

Thoughts for Professionals:

Parents know their child best. They are the primary caregivers and can provide great insight into the child's likes, dislikes, expressions, responses, health issues, and feeding habits, etc. Moreover, a young child is likely to spend the majority of his or her time at home. It is vital therefore, not only to involve the parents in the programme, but also to help them follow it up at home. There are many way to foster this collaboration:

- Provide objective information about the services available and assist the family in using them.
- Maintain a good working relationship with other service providers, and periodically share notes about the child's progress.
- Have regular face-to-face meetings with the parents to discuss the child's educational programme. Invite suggestions from them, and if following the suggestion is not feasible, explain why it is not feasible. Give full consideration to their observation of the child's behaviour at home.
- Invite the parents to the education centre to observe how their child functions with the teacher/therapist and with peers.
- Involve the parents in programme planning for their child. It is extremely important to keep their needs and concerns, their socioeconomic background, and their physical and cultural world in mind. This is especially true for India and other countries where there are wide gaps between socioeconomic classes. This does not mean that the child should not be exposed to anything which is not fully relevant to their world. It is important to expand the child's horizons and give wings to his or her imagination. One needs only to keep in mind that the core of an educational programme should

broadly fit into the world the child has come from.

Moreover, it is easy to hand over a written educational plan to a parent, but carrying it out on their own is not always feasible. It is therefore vital to initiate it together. Paying occasional home visits, even if it is a center based programme, is very valuable. The professional can meet and talk to the other people (such as extended family) in the child's environment, observe home activities that could encourage skills development, and exchange ideas about things that can be changed in the home environment. These interactions ensure a smooth carrying over of programme learning to home learning.

- Keep the parents informed about the child's performance weekly or more often. Parents and teachers can exchange written notes with a diary that goes from home to school with the child. Another way is to have a notice board in each classroom, or maintain a box file for each child that records weekly news. This news may include anything the parent should know—something new the child learned or did, any achievement, big or small, any health or feeding issue, etc. Pictures are always more effective than words, so take lots of pictures of the child doing different things – playing with peers, paging through a story book, looking at the pictures, participating in craft activities, and so on. Caption these pictures and pin them up with the news strip.
- Involve parents in the programme by inviting them to help out with extracurricular activities, during outdoor trips, or while preparing for a function or a stage show. This will help them identify with the programme and also showcase any special talents or skills.
- Regularly provide parents with information and literature relevant to their child's condition. Select articles which are comprehensible, written in a simple and direct manner. Organise workshops and encourage them to share, display charts and posters, share success stories and various developments in the field, show them informative and interesting videos, send them to workshops and trainings conducted by other organisations whenever there is an opportunity. Arrange for childcare while the parents are attending the training .

Thoughts for Parents:

Your child has been admitted to a programme. Trained, caring professionals are there to take care of him or her, but they will need your help in understanding your child's learning needs. Your input is valuable for planning and providing effective services. Moreover, your efforts at home will provide continuity to what your child has learnt at the programme. This will really ensure development on all fronts, in all situations. The intention is not to burden you with big tasks and activities. Just a few simple steps imbedded in the household routine will provide great learning opportunities for your child and facilitate the success of the programme at the center.

Here are a few questions that the parents can ask themselves to start with:

- Do I know my child well enough? I am a responsible and loving mother. I fulfill all my child's needs on time, but do I give him or her a chance to communicate (by touching, pointing, vocalising, gesturing, withdrawing, or in whatever he or she can)? Do I wait and observe my child expressions and movements for a moment before I proceed to put food in his or her mouth, or pick him or her up for a bath? Do I really know my child's likes and dislikes -- games, songs, sounds, etc.?
- Do I talk to my child often in simple language, telling about the objects and people in the environment, helping to touch, see, smell, taste, and explore whenever possible? Do I tell about the things happening around at home – papa going to office, grandpa bringing vegetables from the market, a banana cake being baked for the family, and so on?
- Do I play with my child as I do with any other child without disabilities? Do I play tickle games, finger games, movement games, peek- a- boo, hide and seek, etc.? Do I sing to my hearing-impaired child, keeping him or her close to my body to feel the vibration?
- Do I read interesting little stories to my child in a funny and playful manner?
- Do I involve my child in the family routine -- dinner time or cooking time, for example? It will be convenient for me and interesting for the child to be in the kitchen. I can keep on eye on him or her, and there will be plenty of sensory inputs – the smell of the food, ingredients and spices, the sound of the water falling in the kitchen tap, the cling-clang of vessels, the temperature of a water bottle which comes from the fridge, and above all the sound of mama's voice in between. While eating with others the child is part of the dinner time conversation, hears everyone munching, and sees people passing food to each other. So it is a great lesson in social rules, too.
- Do I involve my child in the full activity instead of bringing things to him or her? Do I take the child to the kitchen so he or she knows where the food comes from, or taking out his clothes from the cupboard together before bathtime? When the soap or shampoo is used up, do I show the empty bottle and take my child to the shop to replace it?

Partnership with Parents: A Different Perspective

The emotional health of the family as a whole, and the fulfillment of the socio-emotional needs of each member is extremely important. Although it may not seem to have a direct bearing on the child's welfare, the family's emotional health affects his growth and education to a large extent. A true partnership with parents, therefore, calls for more than including them in the child's programme or helping them fulfill the child's developmental and educational needs. It also calls for helping them look into their own emotional needs and interpersonal relationships. Only a happy, healthy family can support the all-around nurturing of the child in question.

Viewing parents as individuals in their own respect

How often do we sit with a mother just to have a casual conversation about her as an individual – her aspirations (not necessarily regarding the child), her hopes and disappointments, her expectations, her relationships, her general emotional health? How often do we remind ourselves that she is not just the parent of a special child, but also an individual who, like any of us, has moments of weakness and failure? And personal desires, ambitions, and longings?

It does not take much time or energy to ask a mother a question as simple as, "Do you get time to sit and have a cup of tea with your husband when he comes back from work?" Or "How often are you able to go to a friend's house for a little chat?" Or, "You were a music teacher before you got this child. Do you still sing? Would you like to teach our children once a week?" Or, "Oh! This outfit suits you so well, why don't you wear more of this colour?" The idea is to help them understand that it is OK if they occasionally think of themselves; how they look, what they like, what they would have liked to do in life if the circumstances were different. They can still pursue that dream – at least a part of it. It is also OK, after taking care of the child the whole day, to put the child in grandmother's care and join her husband for a quiet cup of tea. Or to take a round of the marketplace with a friend. These small gratifications will not only enhance the general feeling of well-being among family members, but they will also enhance the level of acceptance for the child.

Helping Parents Find Joy in Interactions with Their Child

The very basis of any healthy and positive relationship is the mutual joy that both individuals derive from it. Especially in the case of the father, where the bonding may require boosters of warm reciprocation from the child, the professionals sometimes need to step in as a facilitators with a few simple strategies:

- **Can we have some fun together?** We need to show how to have fun-filled interactions even with an extremely involved child. There is always something which the parent and the baby can share for some pleasurable moments. It could be a little rub on the arm, a game of tickle, a little walk outside, or a game with a little trinket hung hear the window, and so on. If the child does not seem to enjoy anything then there are other factors we need to look into. Maybe the posture is not suitable, or the father's voice needs to be little softer, or the TV in the background needs to be shut down to avoid too much sound. Maybe the father just needs to roll up his sleeves, because the tactile-sensitive baby does not like the texture of the shirt fabric.

- **What can my child do?** We need to replace so many 'cannot dos' with 'can dos'. Every parent longs to see his or her child achieve, to move forward. And here we are with these little ones with autism and developmental delays, who may progress slowly. So it gives parents a real boost when we are able to show them that the picture is not so bleak, that there are so many things their child can

do and is learning to do. It may be as small a step as tapping on the drum when you tap on it, or giving you his hand as a signal to restart a hand game. Nevertheless, it is sure to bring a smile to the weary face of a parent. That is what a true partnership is – helping them smile through the trials and challenges of parenting a child with multiple disabilities.

Understanding the Siblings' Psyches

It is also important for us to be sensitive to the siblings' feelings and needs, because they can greatly affect the general emotional health of the family. On one hand, a sibling with disabilities may nurture greater empathy, compassion, patience, and sense of maturity and responsibility among siblings. On the other, it may harbour complicated feelings, like resentment about the time, attention, and special concessions given to the sibling. A child may feel discomfort over the difference between the sibling and their friends' sisters and brothers. It is therefore important to find ways to soothe the sibling's nerves, instead of showering him/her with suggestions about their responsibilities towards the child with a disability.

A Few Happy Stories – From the Mothers' Perspective

An experience which brought a fresh breeze in our lives

Seema Sharma (Devakshi's mother)

I am Seema Sharma, the mother of Devakshi (fondly called Chinu), an adorable little girl. I would like to share my experiences at Helen Keller Institute for Deaf and Deafblind. Since Chinu joined Helen Keller Institute there has been no looking back for her, and not for me, either. As a mother of a globally delayed child, who was not using her vision properly, there was a very big question in front of me. I was so lost and did not know what to do, how to stimulate her brain so that she would start using her vision normally.

After coming to Helen Keller Institute's Outreach Programme, within a couple of months Chinu actually started looking at things and taking interest in activities done with her. She slowly started tracking things which were moving and focusing on the ones she was interested in! The sessions conducted here not only helped Chinu in the area of vision but served as a complete developmental programme. The love and affection, the positive approach, the appreciation for even the smallest achievement that these children get here is amazing! I have learnt so many good things here which I never even knew, thing that are so very vital for our children. Having regular conversations with our kids about themselves and the world around them, helping them participate in lots of meaningful and interesting activities, and appreciating them for even a small achievement - these are some of the things which I picked up here and which have added to the emotional and cognitive health of my child. The most important thing that I have learned here is that our children should not be kept out of anything in this world, let it be their daily routine, or shopping, or cleaning, or any other fun activity that the children of their age group enjoy!

Here all the teachers and therapists not only work with our children, but they also guide us and give us courage, hope and advice for our children. We can freely share our thoughts and concerns with them and they all always try to support and encourage us.

I will always be thankful for my association with the people here, as after working with them Chinu has changed a lot and her developmental chart is climbing up every day.

A Few Observations

Arjit is a delightful little one with great potential. He came to us at the age of two and has grown into a smart young boy, displaying great scholastic and musical talent.

Ruchi, the mother of Arijit

Professionals educate the parents about the kids' special needs, and help them understand that special or different efforts are needed to educate the child.

- They help in calming the parents' anxieties and fears, telling them about people who have been there and found success. Parents are absolutely clueless till such organised support comes in.
- They train us to see the sunny side. Every individual has strengths, and encouraging these is important, rather than brooding over what the kid doesn't have.
- They help train fathers who run away from the scene to see things differently. They learn to participate in the process, to give the child all that they would have otherwise given.
- They ground us when we work with our kids like machines, making us realise that our kids too are kids first, special kids second. We have to let them be at times.
- They counsel or sensitise extended families towards the kids' needs.
- They give a place for the parents and the kids to go -- a place where the kid is accepted and loved unconditionally -- a place where there is love and learning.
- The part I loved best were the celebrations and parties and fancy dresses and songs that our kids could also participate in -- a joy for any parent.
- They help us and empower us to move out into more stimulating avenues for the kids -- they help us dream -- they help us live through the dream.

From Kruti, the Mother of 3-year-old Twisha

Partnership with professionals has helped in a big way. It has:

- Helped me in handling specific issues like sensory issues;
- Greatly helped me emotionally. They have always supported and listened patiently whenever I had to share something which was bothering me;
- Provided motivation to keep going. The assurance that things will be better has always soothed my nerves;

My coming here with my child has had an indirect positive effect on my child.





Collaboration at the Government and Local Level: Seeds for Success

Tom Miller, Programme Director, Kevin O'Grady School & Former Director, Perkins Community Partnerships Program, USA
tmiller@nsedu.org
Ron Benham, Director, Bureau of Family Health and Nutrition, Ron.Benham@state.ma.us &
Tracy Osbahr, Early Intervention Consultant, tracy.osbahr@state.ma.us
Massachusetts Department of Public Health, USA

We who work in specialised programmes for infants and toddlers with visual impairments, including those with multiple disabilities and/or deafblindness, can become very protective of our programmes. We advocate for funding without looking at the bigger picture within our local, state, or country governments. We campaign or write letters to advocate for services or funding, forgetting that we serve a low incidence population which many agency and governmental policy makers do not understand. As specialised providers, we understand well the unique service needs of infants and toddlers with visual impairments and their families. However, we cannot assume that the broader early intervention community understands these needs, nor the specialised training and techniques needed to provide effective services. This is a dangerous assumption on our part and one that needs to change.

In order to effect change and the development of our services, we need to first understand that our programmes are a microcosm within the broader macrocosm of early intervention and educational services within our countries. In order to successfully develop our services, we need to become full participants in the range of early intervention service systems within our local, state and/or country. We also have to realise that such change takes time and ongoing commitment to this broader system.

We will illustrate this point through a case study of how the infant and toddler programme at Perkins School for the Blind grew and successfully achieved state-level funding and support, which continues to this day.

In 1983, Perkins School for the Blind started the Perkins Infant and Toddler Program with a grant from the US Government. There were three teachers of students with visual impairments, and staff who provided part-time occupational therapy, physical therapy, speech and language therapy, and social work services. The programme served approximately 20 infants and toddlers and their families per year. These children and their families were also receiving developmental services from state-funded local early intervention programmes.

This small group of students represented a fraction of the children eligible for the services. Given the population and birth rates for the state at that time, there were as many 600 infants and toddlers with visual impairments born in Massachusetts each year. It was obvious that our services needed to expand to meet the needs of a

much broader population of children and their families.

At the local level, the Perkins Infant and Toddler Program was a member of the Massachusetts Early Intervention Consortium, a provider organisation that connected early intervention programmes across the state. Although we were members, we had not previously attended meetings at our regional or state level. The director of the programme began to attend meetings to learn how other early intervention programmes functioned and how they received their funding. It soon became apparent that the professionals in these programmes were unfamiliar with the specialised nature of our services and the unique needs of infants and toddlers with visual impairments and their families. Through regular attendance at their meetings, we began to collaborate more, and referrals to our programme began to grow.

As part of these meetings, we learned how the broader early intervention system within the state was funded. A statewide early intervention advisory board reviewed service and funding issues, and advised the Department of Public Health. After several meetings, the Perkins programme director volunteered to chair the fiscal committee, which considered funding issues across the state and ways to address the growing population in need of early intervention services. The chairperson worked closely with the Department to identify alternative funding sources. This created the opportunity to explore how to fund services to infants and toddlers with visual impairments and their families.

A subcommittee was formed of providers and state agencies who served infants and toddlers with the then low-incidence conditions of visual impairments, deafblindness, deafness, and autism. The group looked at ways to both raise awareness of the unique service needs of these populations, and find ways to fund these services. The formation of this subcommittee by the Department of Public Health was an important step, because it both acknowledged the existence and needs of this population of children and their families, and demonstrated a commitment to include them in service and funding initiatives. This led to the creation of a small pool of funds, which allowed and encouraged early intervention programmes to contract with low-incidence service providers.

The committee developed "child find" brochures, which enabled parents and providers to identify infants and toddlers at risk for visual impairments, deafblindness, deafness, and autism, and refer them for appropriate services. The brochures were disseminated statewide to both the medical and early intervention community. This committee, with the support of the Department of Public Health, also offered a regular series of "red flag trainings" for early intervention providers. The trainings focused on infants and toddlers with low-incidence conditions, and informed the providers of their developmental issues and need for specialised services.

Finally, the committee developed a handbook, *Collaboration Among Families, Early Intervention Programs, and Specialty Providers* (Specialty Service Committee of

the Early Intervention Agency Coordinating Council, 2011), and disseminated it throughout the state. This document stressed the importance of providers conveying respect for the perspectives and content knowledge that all clinicians bring to the table, provided clinicians with a shared vocabulary that was the foundation for continued learning, and offered concrete examples of the benefit to the child and family of a collaborative, coordinated intervention team. The net result of these activities was a dramatic rise in referrals to the Perkins Infant and Toddler Program, which allowed for continued advocacy and investigation of ways to appropriately fund our programme and services. (Early Intervention Parent Leadership Project).

In addition to the above examples of local and state participation, involvement and commitment to the broader early intervention community led to leadership of our federally mandated state Interagency Coordinating Council. This offered the opportunity to represent the needs of children with low-incidence disabilities at the national level. Becoming President of the statewide Massachusetts Early Intervention Consortium, a coalition of providers of early intervention services across the state, also kept the low-incidence agenda visible within provider agencies.

Among all of the above roles that Perkins played, it is important to emphasise that the key focus was on the programmatic and fiscal health of the whole early intervention system, both in the state and nationally. If the early intervention system as a whole is healthy, and we demonstrate our commitment to the service system, it is more likely that our low-incidence programmes will also receive appropriate supports.

What were some outcomes of this collaboration between the state agency and a provider of services to infants and toddlers with visual impairments?

- The Perkins Infant and Toddler Program grew from providing services to 12-20 children per year to between 400 to 500 children and their families per year.
- The staff providing specialised services to these infants and toddlers and their families grew from 3 teachers to 40.
- The programme expanded to serve infants and toddlers across the state.
- Training and collaboration with early intervention programmes across the state led to more effective partnerships between our teachers and local providers, creating a true team approach in service provision to infants and toddlers and their families.
- The programme moved from being entirely grant- and fundraising-dependent to receiving a state contract of $750,000 per year.

Effective collaboration with government agencies and the system of early intervention programmes within any country is a development process and not simply a onetime advocacy event. The above case study evolved over the course of 15-20 years, and continues today due to the ongoing participation of vision professionals from the Perkins early

intervention community in key state and local agencies. As with every endeavor in our lives, this success is founded upon establishing and maintaining connections and relationships that demonstrate our joint commitment to a common cause. In this case, the common cause was early intervention services. Our participation and commitment to the health of the broader early intervention community created support for our programme. This collaboration led to that community and the state agency advocating for and developing a system to support our programme's growth and health.

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Child Find Brochures

- http://www.mass.gov/eohhs/gov/departments/dph/programs/family-health/early-intervention/family-info/specialty-services.html
- Early Intervention Parent Leadership Project, www.eiplp.org

Stereotypies Observed in the Population Served by the ONCE Education Team in the Province of Seville

Inmaculada Costo-Luengo, ONCE Educational Resource Center, Seville, Spain

Introduction

Repetitive behaviours (stereotypies) observed in children and adults, their variability in terms of intensity and manifestation, and the degree to which they are linked to multiple disabilities has led to the following questions: To what degree does the severity of visual impairment account for the manifestation of stereotypies? Why do some blind children not manifest them? And, when are they related to additional impairments or co-occurring ones?

In this paper we use the definition of stereotypy appearing in the book entitled *Introducción al estudio de las estereotipias en el niño ciego.* (Cantavella & Leonhardt, 1992). This definition is based on the one offered by Sambraus (1985) and "encompasses a broad set of behaviours which have the same shared basis, model or fixed pattern, with connotations of abnormality and with a morphologically identical model which is incessantly repeated in the same manner with no premeditated objective", and may take the form of movements or verbal utterances. "Blindisms", the term coined for stereotypies associated with blindness, are included in this definition even though they may differ morphologically from the rest, as they include behaviours such as rubbing one or both eyes, looking at light or head hanging associated with certain activities.

While these are not the only stereotypies characterising blind people, in most cases these behaviours are exhibited only by them.

We observed these behaviours in a sample group that we know and treat on an ongoing basis, either directly or indirectly through other specialists. These specialists provide early care or are teachers who are experts in visual impairments who coordinate their integration in school. Treatment of these behaviours has been a concern for teachers, families, and physiotherapists.

While these behaviours remain morphologically homogeneous, they now affect groups that are in flux. Today our children do not present the same pathologies as children did decades ago. Medical advances and improved healthcare have helped change prognoses, and increasingly, early care provided to families and their children with disabilities has also been instrumental in changing both present and future scenarios.

Methodology

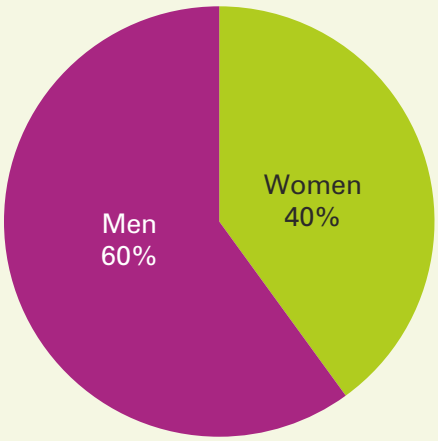
We opted for a survey which we feel is best adapted to a quantitative study. The observations made by early care therapists at the Educational Resource Center (CRE) in Seville, and the teachers who tutor students at the ONCE school in Seville, along with those other teachers who organise their

care at inclusive primary, middle and high schools, have been especially useful to this study. This collaboration has also ensured that the data collected are not one person's opinion but rather reflect extensive knowledge of each participant in the study.

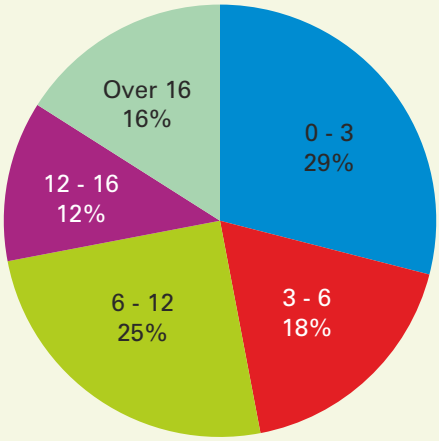
Our sample consisted of 126 babies, children and adolescents, either blind or with maximum visual acuity of 10%. Individuals with low vision (acuity between 0.1 and 0.3) were not included in the sample, as we did not believe we would find stereotypies arising from visual impairment over the 10% acuity threshold. All participants were surveyed during the 2011-2012 school year. A questionnaire was drawn up in braille for students over 16 who use this system, with a view to respecting their privacy.

Practically half of those surveyed were between the ages of 0 and 6. Boys outnumbered girls 75 to 51.

Graph 1. Sample breakdown by sex



Graph 2. Sample breakdown by age bracket



The survey gathered visual acuity information, which ranged from complete blindness to acuity of 10%. The different intervals used follow the classification established in *Trastornos sensoriales: Proceso asistencial integrado* (Justiniano & Tubió, 2010). The first segment covers from total blindness to 0.05 visual acuity[1]. The second segment includes subjects with acuity between 0.05 and 0.1 (people with severe visual impairment) followed by the low-vision segment, which would have included people with acuity between 0.1 and 0.3.

This latter group was not included in our sample as we believe that as from 10% visual acuity, the impairment would not be conclusively responsible for the manifestation of stereotypies. We began with the hypothesis that only the completely blind or nearly blind population is likely to exhibit stereotypies. We did, however, subdivide the first segment into three sub-categories on the questionnaire:

- Complete blindness
- Light perception
- Visual acuity up to 0.05

[1]Visual acuity of 0.05 corresponds to 5%. In the first case, the figure is related to the unit while in the second it is a percentage. Vision of 1 (100%) is normal. Wherever possible, these are optically corrected visual acuities.

The aim of added sub-categories was to more accurately specify the moment at which stereotypies caused by vision impairment appear.

We added a last interval covering visual acuity between 0.05 and 0.1. It is a proven fact that children with visual acuity in the vicinity of 0.05 are able to follow the learning process on how to read and write printed texts. While this does not mean these children undergo a normal development process, it does give us an idea (with all reservations relating to personal effort, support mechanisms, etc.) of what we are talking about when we refer to these low acuities.

We also stress the importance of the moment at which the visual impairment appears in the life of the child. Children born with normal vision and who lose their sight at some later date do not generally exhibit stereotypies. This fact is corroborated by the study conducted by Cantavella and Leonhardt (1992*),* which affirms the lack of blindisms in children with acquired blindness. However, we have observed these phenomena if sight is lost at a very young age. There is typically an interval of between one and two years after the loss of vision until the onset of the stereotypy.

We therefore pose the question of the innate or acquired nature of the impairment and the moment at which it appears, and how it affects the development of stereotypies. This will allow us to determine whether or not a child is likely to exhibit stereotypies. It will also allow us to determine the threshold age at which a child can lose his sight and not be expected to present these behaviours. This is very important for us because in recent years we are seeing an increasing number of children who were either born sighted and then lost their sight due to an accident (other senses remaining intact) or who were born with limited sight and subsequently became blind. Treatment and development of these children is different from that of those born blind or with multiple disabilities. For both groups there is sufficient literature to guide us and scales of specific development we can use for support, but the group surveyed is different from both of these. This line of research, over and above the results obtained from the sample, and the fact that this is a cross-sectional study, demonstrates our interest in delving deeper into this issue, clarifying doubts regarding how to approach this growing population.

Determining the existence of other disabilities is a priority insofar as this allows for a distinction to be drawn between these repetitive non-functional behaviours arising from visual impairment and those that may be the result of some other syndrome or organic problem related to these other disabilities. Our aim is to shed light on the correlation between the morphology of stereotypies linked exclusively to visual impairment and those related to other disabilities.

We are also interested in knowing how these evolve over time. Children often engage in repetitive behaviour which, observed in an isolated situation, could be interpreted as a stereotypy. However, we know that in many cases this behaviour is part of a developmental process and tends to disappear. Only when they persist over

time can these behaviours be considered as a pathology and be called stereotypies. Even on these occasions we need to exercise caution because our population needs longer periods to consolidate learning and this could lead us to mistakenly classify behaviour as a motor habit rather than an evolving stereotypy or a normal developmental stage. That is why the survey asks whether they currently exhibit or have exhibited stereotypies at any previous time.

In addition to the work done with children in the early care programmes and support received at school from teachers who specialise in blindness, the evolution of this sort of behaviour can also be affected by the blind person's awareness of it and the concern expressed by the family. Therefore, the survey asks whether they have tried to eliminate these behaviours and, if so, if they were successful. We are interested in knowing whether the child has been successful in controlling the behaviour at any point in time and especially whether this control persists over time or is permanent. We also want to know how this control was achieved, i.e., through professional therapy or the willpower of the person who decided to eliminate these behaviours. Hence, this work which is a cross-cutting analysis of a specific population at a specific point in time, can shed some light on the evolution of these behaviours.

While it is not our intention to investigate the aetiology of these behaviours as this would entail a longitudinal study, we do look at the emotional state linked to them, establishing relationships between certain situations and their effect on the children. Lastly, we were interested in knowing the parents' reaction to these behaviours. Although fathers are increasingly involved in all the facets of their children's lives, this question was broken down by sex as it is still the mothers who want to or have to be involved in their children's lives.

The age groups associated with many of the survey responses adhere to the major development guides and scales which, in turn, consider milestones reached by certain ages. The first group is 0 to six months. The second is from six months to one year, from one year to two years, and from two years to three. The next group is age three to six, coinciding with the second stage of pre-school, and then on to primary school, secondary school and finally the over 16 group.

A statistical analysis of the data was performed to quantitatively assess these behaviours and compare these figures with the degree of visual impairment, the moment at which it appeared and the presence (or not) of other problems.

Results

Hypothesis 1: “Only the completely and nearly blind group is likely to exhibit stereotypies exclusively associated with their visual impairment”.

We drew a correlation between degree of visual impairment and stereotypies. To that end we looked at the different degrees (intervals) of visual acuity and eliminated subjects with additional impairments.

In the first interval, consisting of participants who were totally blind, 92% of those who had no additional impairments exhibited stereotypies.

In the third interval (acuity up to 0.05) there was a negative correlation between increase in visual acuity and the likelihood of exhibiting stereotypies; in other words, the greater the acuity the less likely that the person would exhibit a stereotypy.

In the last interval, where visual acuity was higher (between 0.05 and 0.1), the incidence of stereotypies continued to decline. Despite this trend, we believe it would have been worthwhile to include the low vision population in the study to more clearly confirm the absence of stereotypies the further one gets from blindness.

The only interval that does not follow this trend is the one encompassing those who perceive light. There were five people in this group, three of whom exhibited stereotypies and two who did not. This segment is difficult to demarcate and for families and professionals to understand, as ophthalmological measurements are used to determine visual acuity and rarely take light perception into account. We therefore believe that we could eliminate this interval as it does not contribute relevant or reliable data.

Hypothesis 2: "When total blindness is acquired, stereotypies do not appear unless blindness was acquired at an early age".
It is a verifiable fact that there are people who are completely blind that do not exhibit stereotypies and there are children who develop them after losing their vision. Why do some children, adolescents and adults who have lost their sight have no abnormal motor or verbal behaviours? They may have exhibited such behaviours at some point and managed to permanently eliminate them or they may never have manifested them at all. We believe that in most cases this depends on the age at which sight is lost. Our aim is to determine the time conditions under which stereotypies manifest themselves both in terms of the age at which sight is lost and the time that elapses between sight loss and their onset. We are referring to healthy populations who are diagnosed with visual impairment only. Of the eight people surveyed who lost their sight at different moments in their lives, seven lost it before age three and all of them eventually developed stereotypies except for one completely blind girl who lost her sight at the age of 20 months and who was studied at 24 months. The eighth person surveyed lost his sight at age five and also exhibits stereotypies.

Table 1 :
Presence of stereotypies in conginetal vs acquired blindness

conginetal or acquired impairment	Age at which sight is lost	Stereo-typies	Other Pathologies
Acquired	From 0 to 6 months	Yes	No
Acquired	From 0 to 6 months	Yes	No
Acquired	From 6 months to 1 year	Yes	No
Acquired	From 1 to 2 years	No	No
Acquired	From 1 to 2 years	Yes	No
Acquired	From 1 to 2 years	Yes	No
Acquired	From 3 to 6 years	Yes	No
Acquired	No answer	Yes	No
Congenital		Yes	No
Congenital		Yes	No
Congenital		Yes	No
Congenital		Yes	No
Congenital		Yes	No

The sample size is very small but representative in terms of age intervals and conclusive in terms of the unanimous manifestation of stereotypies. We have no data about people who lost their sight after age five or other representatives of that last age group to sufficiently support the precocity hypothesis referred to above as necessary for the emergence of stereotypies. We are therefore unable to determine the threshold at which it can be assumed that these behaviours will not manifest themselves. Hence, we are unable to corroborate this second hypothesis owing to an excessively small sample size of people in this older age group.

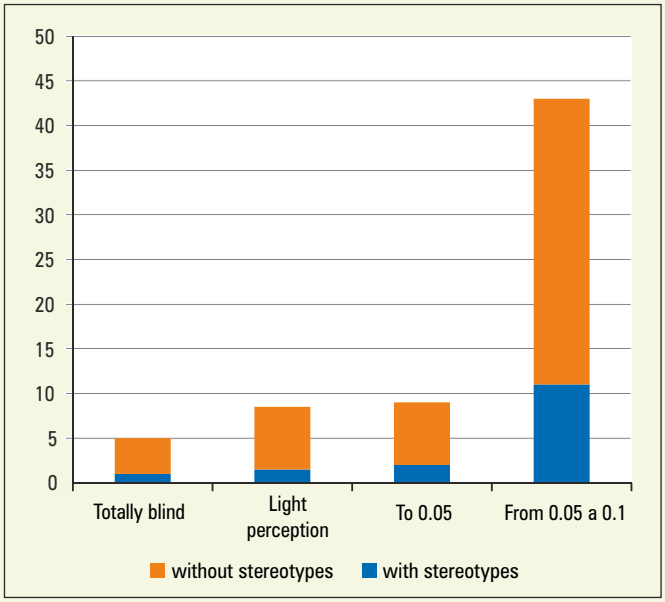
Hypothesis 3: "When people with greater visual acuity do manifest stereotypies, they are affected by other additional pathologies".

While this paper does not focus on the aetiology of stereotypies, we believe that the severe sensory deprivation that our children suffer makes development especially difficult. This is not exclusively due to the lack of information received by these children. How they perceive the world around them, how they feel immersed in or separated from it, contributes to the manifestation of these behaviours. In contrast, when these children have the opportunity to interact visually with their surroundings, their difficulties decrease enormously. This also opens the door to learning by imitation and the possibility to correct body postures and movements that are not socially acceptable. This does not happen in the case of multiple disabilities. Most of the literature on this subject focuses on stereotypies in populations that are not visually impaired. We have therefore drawn a correlation between stereotypies in the population with additional disabilities with factors unrelated to sight.

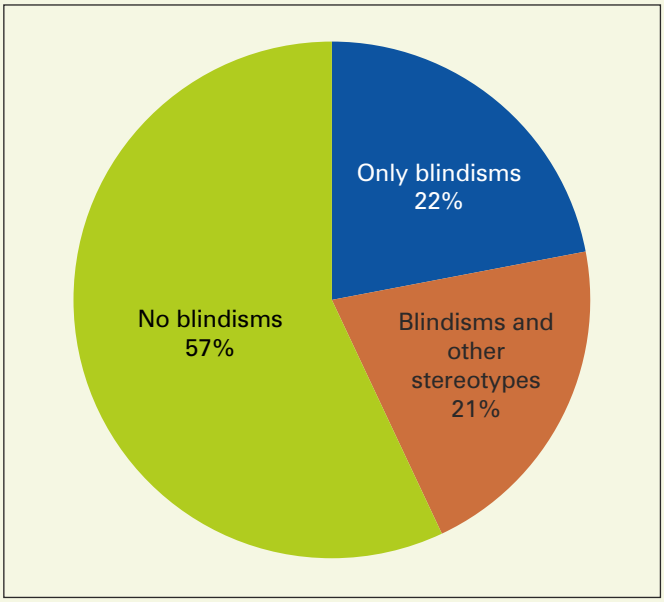
In our sample, the totally blind population with no additional disabilities always presents stereotypies, except for the one case mentioned above. These behaviours decrease as acuity rises and stand at 21% when acuity is between 0.05 and 0.1. In contrast, if we analyse the population with multiple disabilities we find a higher percentage with stereotypies, even in the group with greater visual acuity. And this is without considering that ophthalmological assessments tend to reflect lower vision than is actually the case due to lack of cooperation.

In conclusion, stereotypies manifested by subjects with higher visual acuity were clearly related to causes other than poor vision. However, we also found children and adolescents from the highest acuity group and no additional impairments who did exhibit these behaviours. This could be due to a lack of aetiological diagnosis supported by medical tests in certain cases, and to the fact that within this segment of higher acuity there are cases of severe vision loss where stereotypies are still detected.

Graph 3 :
Stereotypies in subjects with multiple disabilities and visual impairment



Graph 4 :
Morphology of stereotypies in healthy people with visual impairment



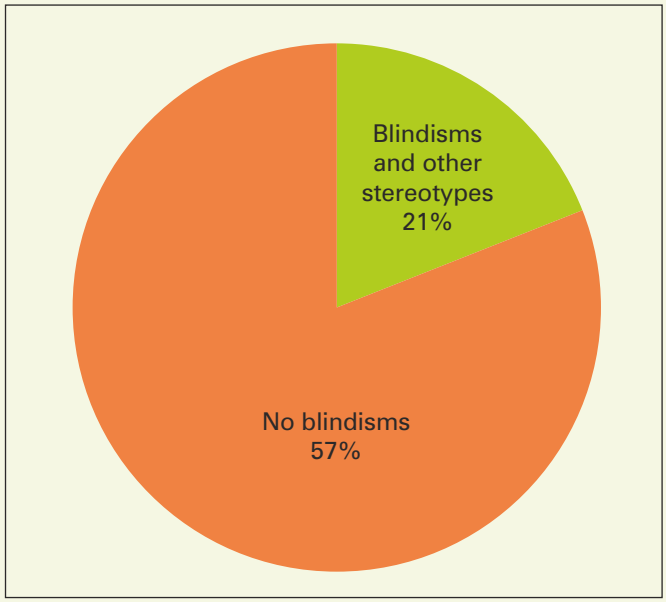
As for our aim of drawing a correlation between the morphology of stereotypies associated exclusively to visual impairment (e.g., blindisms, head hanging) and those associated with other disabilities, it is safe to say that 50% of the totally blind subjects with no other disabilities exhibited stereotypies of the same characteristics that we call blindisms, and half of these do not manifest any other sort of anomalous behaviour. In other words, these blind subjects exclusively exhibited these types of stereotypies. Even so, we are not able to clearly establish the existence of differentiated stereotypical behaviour deriving from visual impairment and other behaviours arising from other types of impairment. The type of stereotypies manifested by healthy visually impaired populations are similar to those exhibited by autistic persons, i.e. hand flapping, rocking, head movements, together with the so-called blindisms (many different forms of eye rubbing, looking at light, and head hanging).

This study was also intended to shed light on the degree of concern on the part of those affected and their families regarding these behaviours and the difficulty encountered in eliminating them. In nearly all cases, stereotypies make people uncomfortable and they therefore try to eliminate them. The families especially express greater concern over these behaviours they consider abnormal and which keep their children from integrating with others. We would note that this greater concern usually begins when their children are enrolled in the second stage of pre-school and rarely before. Those over age 16 who acknowledge having stereotypies did not express any particular urgency on the questionnaire to do anything about them.

Analysis of the sample showed that stereotypies may be consciously controlled but this suspension of motor or verbal activity is very short-lived and permanent elimination is very rare. Fifteen of those surveyed were able to suspend their

behaviour for an instant and a further 22 kept them at bay for a minute but they returned shortly thereafter. Of those surveyed, only one managed to permanently eliminate these behaviours. This was a boy over 16, with no other disabilities, who believed that these behaviours were isolating him socially and he managed to eliminate them with professional help. We would particularly stress this latter observation as we believe that his willpower helped him to eliminate them. Of the rest of those surveyed over age 16 who admit to having stereotypies (7), only three believed that these behaviours isolated them socially.

Graph 5 :
Morphology of stereotypies in healthy people with visual impairment



Responses were quite varied regarding the correlation between state of mind and the expression of stereotypies. The most common were boredom (23), isolation and nervousness (17), joy (14), anxiety and anger (11), concentration (7) and fear (only 3). In many cases, observation of these states and the emotional situations surrounding the undesired behaviour can facilitate intervention and give children greater control over their environment and help them suppress said behaviours. The responses received from parents to the question about the emotions that spark a manifestation of stereotypies shed little light on the situation. Only 58% responded to the question and ticked several different emotional states such as nervousness, sadness or indifference. It is difficult to assess these feelings as families are not used to talking about themselves in this way.

In the sample there was a special category of deafblind children requiring very specific treatment, but without forgetting that this handicap may be accompanied by other impairments appearing in the sample. In this regard, there were four deafblind subjects and only one exhibited stereotypies and a further four deafblind subjects with multiple disabilities, three of whom exhibited stereotypies. All were in the highest visual acuity segment except for one person with acuity under 0.05 and one other person who did not know or did not answer.

Over and above the quantitative results obtained from the survey, we place a priority on action taken in the first years of the child's life. This early action is what attenuates many of the behaviours which otherwise would become stereotypies and which therefore may not have appeared in our sample. It is very important to gain a deep understanding of the child's reality and come up with suitable responses to their needs. Family support in the form of parenting guidelines from the early care

teams can help channel many of these behaviours and catch them in time so that they do not become pathological. This is essentially prevention work that our professionals reflect in the questionnaires in the section for "observations". Their experience and knowledge of the development of healthy children compared with those with disabilities puts them in a position to sound the alarm in the event of unexpected behaviour. This sort of intervention is what truly prevents the development of many of these behaviours when families have not yet perceived them.

Our intention has been to conduct a quantitative study of the specific population we treat, a population that has evolved with respect to preceding decades in terms of type of visual pathology, cause of the latter, the point in time when it is acquired, and the degree to which it is associated with other impairments. We then want to spark discussion to help us better understand our patients' possibilities and their circumstances. Once we have gained this understanding, we are in a better position to offer them proper care. Our goal is to have healthy children who are happy despite their impairments. The population we are referring to includes families because that is where children develop and we can only expect to improve the development of the children if we support and accompany families.

Discussion

The discussion that we have initiated by reporting that stereotypies can develop in cases of acquired blindness is not over. It is generally believed that these behaviours are only manifested by people with congenital visual impairments. Authors such as Cantavella and Leonhardt report that acquired blindness is not accompanied by stereotypies but in our sample these behaviours did develop in all of the cases of acquired blindness. We have not had the opportunity to study subjects who lost their sight as adults but it is very likely that all of the blind people with no stereotypies belong to that age group. Therefore, further study is needed to determine whether the age at which the impairment is acquired is a determining factor in the development of stereotypies or whether other factors come into play.

As already stated in the introduction, there is a positive correlation between the seriousness of the visual impairment and the manifestation of stereotypies. We have been able to quantify this perception with data obtained from our sample although we have not been able to establish a clear threshold beyond which they do not appear. Other studies have included subjects with low vision who exhibited these behaviours but we were interested in separating those caused by a visual impairment from those with a different aetiology. There are different opinions regarding low vision and the authors do not specify what acuity they are referring to when they use this term in their research. We use the classification established in *Trastornos sensoriales: Proceso asistencial integrado* and we would urge everyone to use this classification and no other when referring to the different categories of visual impairment. In any case, if we had included low vision in our study we may have been able to better explain our hypothesis.

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The Childrearing Experiences of Korean Mothers of Children with Visual Impairments

Sangeun Oh, Professor / College of Nursing, Chonnam National University, Republic of Korea
seoh@chonnam.ac.kr

Introduction

Visual loss in childhood has lifelong and far-reaching consequences, for the affected child and family, and for society in general (Jan & Freeman, 1998). Children with vision loss experience restricted interactions with their environment, and limitations in the scope and diversity of their everyday experiences (Lowenfeld, 1981).

The most serious problem that an infant's visual impairment creates is interference in the parent-child attachment process. The pair cannot share emotions and communicate by seeing one another's facial expressions. Mothers whose children have visual impairments (VI) feel set apart within the socio-cultural context of Korea.

In order to provide holistic care to families and their infants, providers must know and understand their lives and circumstances (Oh, 2000). In order to comprehensively explore the experiences of mothers of children with visual impairments, the researcher chose the qualitative study method of Symbolic Interactionism. This is an interpretive science that aims to represent and understand the process of creation and the meaning humans assign to the reality they live in (Charon, 2007). According to Symbolic Interactionism, human behaviours are formed by means of interactive construction. The specific qualitative approach to this study was Grounded Theory, based on Symbolic Interactionism.

The objective of this study was to analyse the experiences of Korean mothers of children with visual impairments, exploring in depth the meaning and the process of their childrearing experiences. The findings of this study will increase knowledge and understanding for nurses who provide services to these families. This study also provides source data for the family nursing programme, which includes children with visual impairments as well as their families.

Methods

Grounded Theory methodology was chosen for this study. The goal of Grounded Theory methodology is to generate a substantive theory that accounts for key social and psychological processes in a particular social setting (Stern, 1980). Such a theory will be empirically grounded and work properly with the specific group of participants, in this case Korean mothers of children with VI. This approach starts with a question, and allows the theory to arise from analysis of the data. The data is systematically obtained and analysed by constantly comparing them, from collection to analysis and analysis to data collection (Glaser & Strauss, 1967).

The university hospital ethics committee approved the study with written consent. Five participants were selected, Korean mothers aged 32 to 40 whose children with visual impairments were between the ages of 3 and 14. Two of the children had

congenital macular degeneration, and three had retinopathy of prematurity. All children were born with prematurity, and two of them were born with twins. The participants were all informed about the study objectives and signed the consent form.

The data were collected by semi-structured individual in-depth interviews at the participants' homes. Data was collected all the way to the theoretical saturation, the point at which there was repetition and lack of new information. The audiotape interviews lasted between 50 to 120 minutes, and were transcribed verbatim. The strategy used for category development was the constant comparative method (Glaser & Strauss, 1967).

In compliance with Grounded Theory methodology, the researcher read the transcripts line by line, in an attempt to answer the question, "What does this incident represent?" Codes were established which reflected the substance of what was said. Theoretical memo writing was initiated in a simplified form, becoming more complex as the analysis proceeded. Sorting of theoretical memos provided the impetus for theory formation. The three stages of Grounded Theory Approach are as follows (Strauss and Corbin, 1990):

1. Open coding, a procedure for developing categories of information;
2. Axial coding, a procedure for interconnecting the categories;
3. Selective coding, a procedure for building a story that connects the categories and produces a discursive set of theoretical propositions.

We chose to work with *in vivo* codes, which help us preserve the meanings of the participants, retaining their own concerns, opinions, and behaviours in the coding. Codes were grouped one by one through the comparison process, by their similarities and conceptual differences, to form categories. Categorisation is a process of grouping concepts that prove to be relevant and are part of the same phenomenon.

After exploring the relationship of categories, the connections were made between them. In the final stage of data analysis, the central phenomenon is to find the link between categories and a higher level of abstraction. Then a model was applied to the defined central phenomenon. The model has five steps: causal conditions, central phenomenon, context, intervening conditions, action/interaction strategies, and consequences (Strauss & Corbin, 1990).

Results and Implications

1. Core Category: Be a Light for the Child

A core category means the category under which all other categories can be subsumed (Strauss & Corbin, 1990). The core category about the process of rearing children with VI is “be a light for the child.” This was a very basic social-psychological process that appears implicitly.

2. Causal Condition: The Child is Diagnosed with VI

Causal condition means a phenomenon that explains reasons and conditions (Strauss & Corbin, 1990). In this study the diagnosis of a child with visual impairments

was the causal condition. After difficult premature births, the mothers noticed their babies did not make eye contact. Later, when visual impairment was diagnosed, they experienced shock, sorrow, and anguish.

3. Central Phenomenon: Wish for a Cure for the Child's Vision Impairment

The central phenomenon means the central idea, event, happening, or incident about which a set of actions or interactions are directed, with the hope of managing or handling it (Strauss & Corbin, 1990). When the mothers learned of their babies' visual impairment, they couldn't help wishing for a cure and normal vision for their children. At the same time, they experienced sorrow and heartbreak because the children with VI couldn't make eye contact.

4. Context: Lack of Public Awareness About VI

Context means locations and situations of events (Strauss & Corbin, 1990). The mothers felt uncomfortable leaving the house with their children, because they encountered insensitivity, ignorance, and unwelcome pity. Sometimes strangers would ask, "What happened to the kid?" One of the participants took her child to the hospital for treatment, and was upset when a staffmember told her that visual impairment is not a lifelong disease.

5. Intervening Conditions: Holistic Maternal Love and Family Conflicts

Intervening conditions may shape, facilitate, or constrain the strategies that take place within a specific context (Strauss & Corbin, 1990). In this study, intervening conditions were "holistic maternal love" and "family conflicts". Even though the marital relationship and family had crises because of the child with visual impairment, the mothers selflessly and lovingly took care of their children.

6. The Strategic Action/Reaction

The strategic action/reaction means addressing the phenomenon in a purposeful and goal-oriented way (Strauss & Corbin, 1990). In this study, the strategic action/reactions for coping and problem-solving were:

- Attempting to find a cure for the child's visual impairment;
- Swallowing the sadness of the child's blindness;
- Praying for the child's eyes to be cured;
- Enduring difficulties;
- Trying to empower the child;
- Controlling the body and mind;
- Normalising growth and development of child with VI;
- Giving up supports of family members;
- Using the social-welfare system;
- Participating in maternal and educational meetings;
- Learning braille with the child;
- Ignoring others' prejudices.

The consequences were that the mothers "gradually adjusted themselves to their given condition" and "harmonised life just like any other ordinary parents."

7. The process of rearing children with VI

The core category in the study was "be a light for the child". Each mother's experience and process had three phases:

1. Entering a dark tunnel;
2. Facing the darkness and struggling;
3. Finding hope and escaping from the dark tunnel.

The process was an orderly progress as time passed and the children grew. The contexts, intervening conditions, and behavioural/interactive strategies are connected differently to each level.

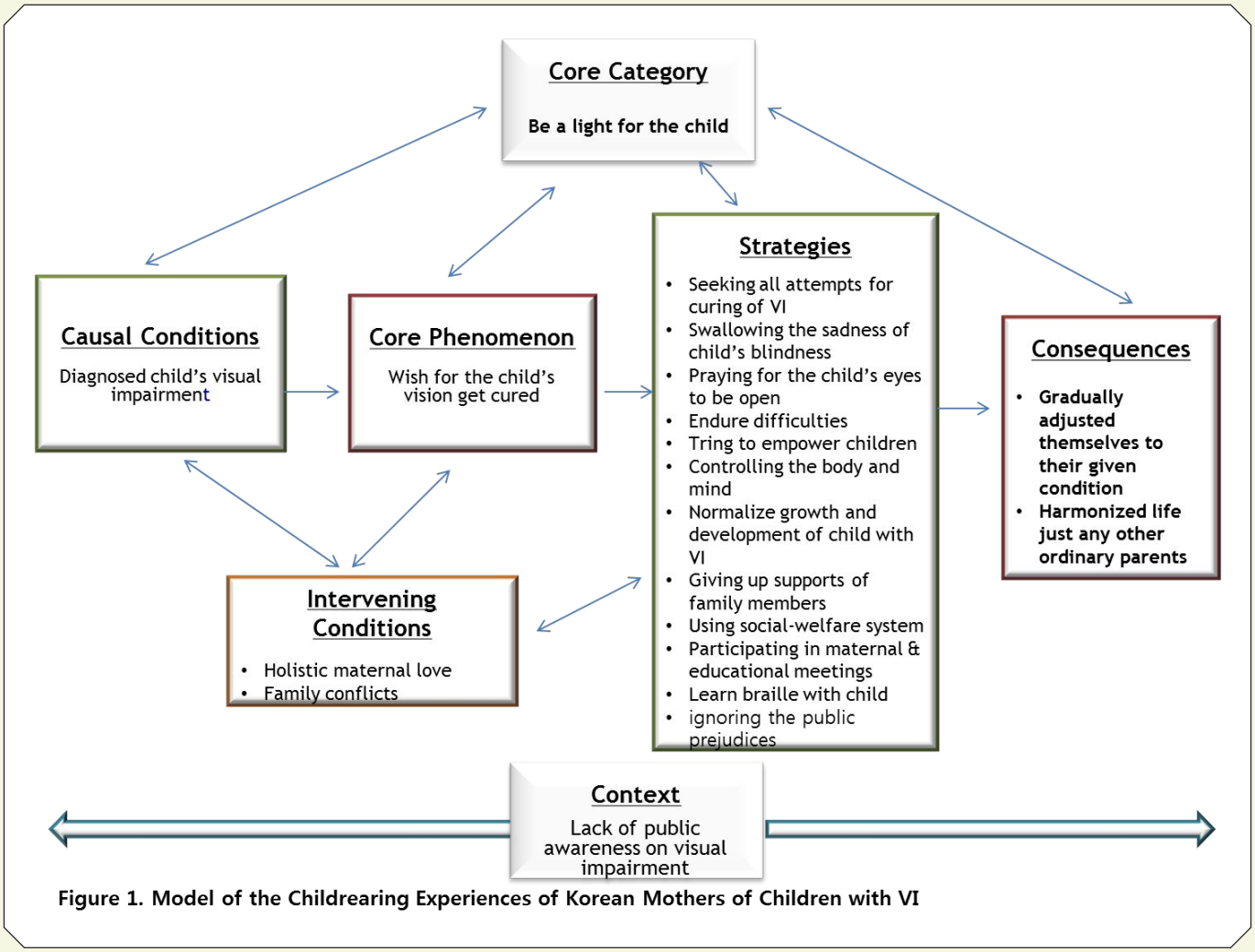


Figure 1. Model of the Childrearing Experiences of Korean Mothers of Children with VI

1. Entering a Dark Tunnel

The mothers were in shock and misery because their children were diagnosed with visual impairments. In terms of context, the participants experienced difficulties and frustrations because of the sociocultural prejudice and lack of public awareness about visual impairment. They felt like they were entering a dark tunnel.

2. Facing the darkness and struggling in the tunnel

The mothers were anxious about their children's safety and the future. They overprotected their children and endured difficulties while praying for the child's eyes to be cured. They became a light for their children and looked for the possible treatment options. This made them feel like facing the darkness.

The babies' visual impairments created significant strain on their families. The families often found their friends and relatives unsympathetic and unsupportive, mostly because they don't understand about visual impairments. The families need to create that understanding, finding the confidence and courage to speak up. They can educate their families and friends about their children's disabilities.

While the mothers created safe growing environments and sought medical treatments, they coped with emotional and physical struggles. The fathers were patient and worked to financially support the family and meet medical expenses. With the mothers involved in caring for the children, and the fathers facing the financial responsibilities, many couples spent little time together. This led to marital crises and conflicting ideas on the child-rearing. Meeting nurses who specialise in couple therapy and family therapy would improve the marital relationship.

3. Finding hope and escaping from the dark tunnel

Finally the parents accepted the reality that their children's visual impairments were incurable. They started to see the light in the dark tunnel when they realised that their children were happily growing. Even though the children remained visually impaired, the parents realised that their children grew just fine, just like any other children. They started to participate in education meetings for parents with visually impaired children and received social welfare. They learned not to be overprotective, and taught their children how to be independent and perform many tasks of daily life by themselves. The parents learned braille reading with their children, and tried to establish understanding and good relationships with their relatives.

The nurses who work in the local health center need to encourage the parents of visually impaired children when they visit for child vaccinations and other services. They can teach parents not to be overprotective, and show them how to maximise their children's normal growth and development. The nurses should also distinguish the mother's parenting styles first, then help them to enhance their positive strategies and change the negative strategies.

Meanwhile the mothers realised that their happiness is not determined by their children's visual impairment. One mother took her child to the hospital, where she met a woman who seemed happy, even though she also had a young daughter with a visual impairment. The new acquaintance said, "Even though the child cannot see, she is still God's gift. So I am taking care of her like Jesus' heart who was crucified for our sin." Suddenly the mother realised being happy has nothing to do with visual impairment. Other mothers experienced similar turning points, realising their children were just same as any other children. At this stage, the parents found social-psychological stability. They started actively participating in their children's education. These parents could play an important role in the support group.

As children with visual impairments grow and develop, their rehabilitation routine

should change to accommodate their new directions. The parents' support association plays a significant role in successful adaptations. These parents' groups are mainly associated with specialised schools for children with visual impairments. A nurse from the local health center should be a mediator for expanding the association's activities, from school-based concerns to activities in the local communities. The parents' groups can also invite special educators and other professionals to encourage the development, hopes, and dreams of children with visual impairments.

Consequences

Even though the mothers of visually impaired children initially encountered difficulties, they learned to pursue a harmonised life. Although sociocultural prejudice against children with visual impairments still exists in current Korean society, these parents freed themselves from the judgments and biases. They hope to cultivate their children's potential talents, and they want to help others who were dealing the same struggles and problems as themselves.

Conclusion

In the process of rearing children with VI, mothers gradually adjusted, with devoted maternal love. They came to accept their situation, and strive to enjoy a harmonised life just like any other parents. They also they gained problem-solving strategies as they learned to care for, protect, and educate their children with VI. Health care providers can establish supportive programmes in the clinical field to empower these mothers, by supporting their proactive coping and problem solving strategies. The findings of this study provide a theoretical ground for planning family nursing intervention for parents of children with VI and their family members. Also, these findings can change public awareness of children with VI.

By revealing the childrearing experiences of mothers of children with VI within Korea's socio-cultural context, this study is expected to have several effects.

- First, it will contribute to the expansion of knowledge in nursing. It will provide basic information regarding the development of nursing practice and theory, and increase understanding of children with visual and other sensory disabilities as well as that of their families.
- Second, this better understanding of the experience of mothers of children with visual impairments will enhance child health nursing education for undergraduate and graduate students. It will improve classroom educational materials for parents of children with visual impairments.
- Third, this foundational work will help to develop nursing interventions intended to promote the growth and development of children with visual impairment.

Moreover, the results of this study will be provided to community health professionals, social workers, scholars, and practitioners in family-related academic fields. The results will provide the basic material necessary for them to help normalise families with visually impaired

children. They will provide a broadened understanding of the experiences of these families and help to avoid their simply being characterised as families of disabled children.

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Partnership with families: "For the welfare of your child"

Ana García-Arcicollar Vallejo, ONCE Early Intervention Team, Madrid Spain
ana_kamp@hotmail.com

As an Early Intervention Specialist, I daily confirm the importance of family partnerships in fostering the good development of the child.

When I say family, I am referring especially to moms and dads. Years ago, children used to come to our sessions with their mothers, with fathers only occasionally participating. More recently, it is quite common for children to arrive with both parents, or only with their dads. The role of the caregiver is no longer exclusive of the mother or the female figure. It's important to remember as well, that grandparents, uncles, and others devote their time to the care and upbringing of the child. Sometimes they are the most responsible adults in the child's life.

When I first became an Early Interventionist, I was a little bit uncomfortable about the family's presence in the session. I used to feel they were judging me as I worked with their child.

Eventually I realised that it is we professionals who are most often are judging the families. Based on what we see in the sessions, we assess whether the parent-child bond is adequate, whether the parenting methods are appropriate (breastfeeding, co-sleeping, use of the pacifier, diapering practices, moment of separation, limits, etc.). We tell ourselves that our judgment is, of course, in order to help the child, because "if the family is not doing well, someone has to advise them to correct it".

When I myself became a mother of a visually impaired child, my perspective changed. As a professional, I knew that the family goes though a mourning process, but I didn't live it. As a professional, I knew the spiral of doctors and medical care is terrible, but I didn't live it. As a professional I knew what has to be done, but I didn't consider whether it was possible to carry out my advice. As a professional I knew what the child should be able to do at a particular stage of development, but I didn't consider the extreme emotional experiences that the child can be living through. As a professional, I knew about current theories of parenting, but I didn't knew which one was needed by each individual family and each child.

As a parent, I had the opportunity to sit on the other side of the table. I lived through very difficult invasive medical tests with my son. I felt enormously guilty for allowing the medical professionals to do this work. I experienced the sensation of entering a medical or evaluation session with doubts about whether it was good for my child, having been persuaded to "do what my child needs". I received doubtful and uncertain diagnoses or, as I prefer to call them, "unfortunate" diagnoses, all of them delivered to me with supreme professional

confidence. The diagnoses were about my child's vision, language development, postural difficulties, and even breathing problems. Because a child with disabilities is specially monitored, there are often false alarms. All of these experiences are a hard burden for families.

I have to say that I also found professionals who made me feel especially well. They welcomed us with understanding, and they knew how to adapt themselves perfectly to our characteristics. I thank them for serving as models for how to be a professional.

I had difficulty with these experiences even though I had advantages that other parents don't have. I was already working in Early Intervention with children with visual impairments. My parents are totally blind, and they brought me up and educated me. I am visually impaired, and my husband is, too. We knew there was a possibility that our baby would be born with a visual impairment. Therefore, it didn't catch us entirely by surprise, nor were we misinformed, but it was very hard anyway.

Although it has been a hard personal experience, it has been a very enriching professional experience, because I have come to understand many things. Among them, I have insight into why sometimes our work does not bear the fruits we expect. There are cases in which we suspect families of refusing to cooperate. We need to realise that sometimes we professionals are the ones who are going at it wrong. Often we are simply failing to create a bond with the family.

We often approach families with the assumption that we know best. We arrive with our preconceptions about the child's needs and methodologies, and expect the family to become engaged with our approach. Instead, we are the ones who have to seek and find the most appropriate way to connect with the family. This implies a need for respect, understanding, and sometimes a lot of patience. The emotional process sometimes cannot follow the rhythm we would like, but we must wait quietly for the right moment. That moment always comes if we give things the room and importance they deserve.

Families are burdened with all kinds of opinions and criteria and from all directions: pediatricians, medical specialists, teachers, counselors, other education professionals, neighbors, friends, strangers, and other family members. All of them are sure they know best, but none of them are living that family's reality. All of the “you should” opinions are just more burdens. When the professional advice does not conform to the concrete reality of the family (social circumstances, emotional moments), it is far from helpful. It worsens the situation and increases the family's feeling of guilt, a burden they will carry for a long time.

We cannot forget that families generally leave the hospital with their babies a few days after birth. Even if they have many visits with doctors, intervention centers, and others, it is their parents with whom they spend the most time. It is they with whom the baby enjoys the quiet moments. Therefore it is the family who knows the child best and who can best assess his or her mood. *That is, the experts in each child's situation are his or her own parents.*

It is true that the emotional shock and overload can hinder the family from seeing the child as a child. Sometimes at first they can only see the illness, and it may seem that caring for the welfare of the child falls to the professionals. However, our role as professionals is to support them, to help them regain their self-confidence, and realise that they are experts about their own children.

I have found that when a family feels understood and accepted, they become much less anxious and willing to accept support and professional help. When the family is more relaxed, they are also more receptive to any small advances and suggestions. They are more likely to value the emotional state of their children, which is exactly what deepens their relationship. When the child feels secure, safe, relaxed, he or she is likely to show advances in development.

How do we make the family feel understood and accepted? How do we create that bond?

I have learned that the first contact is very important. It sets expectations, and allows us, as professionals, to start providing the family security and comfort. I have discovered that starting the professional job without taking time to create communication creates many doubts for the families (that maybe they resolve with time or not). But in any case, we lose a fruitful working time when we are not in line with the family's needs.

At the beginning, it's important to state clearly *who we are*. We are normally part of multidisciplinary teams, and the family does not know who they are talking to -- a teacher, a counselor, a social worker, an auxiliary, etc.

Next, it is necessary to explain what will we do, and how. Sometimes the family has expectations that the child is going to gain vision. It always helps them to understood from the beginning that we are not doctors. We can't make the child see more, but we will try to help maximise whatever vision may exist.

That is when we show that our work is not only with the child, but *with the family*. This is essential. Because if the family doesn't feel well, the child will not feel well. Therefore, I offer to answer anything the family needs to ask about. I make sure they know I am willing to repeat things many times, until they are sure they understand.

It is good to emphasise that the families are the experts that best understand the child, and that they can help us to understand him or her. They can help us make the child more comfortable. In addition, the time they spend with us is minimal compared to the time the baby spends with them.

Then we together agree on the frequency and duration of the sessions. Given that the children are very young, the duration may vary a little, either because they tire easily, or because we need to consult with the family.

The most important thing in this first contact, is to tell the family all the positive aspects we have observed, both in the child and the family. Families leave each medical session, treatment, and school

meeting loaded with problems and outstanding issues they have to solve as “homework”. Being able to share a space where the professional understands and accepts the child is immensely rewarding and constructive for the family. It is like an “energy kick” for the parents to be praised for doing things well.

As we spend time together and trust is being established, the family usually begins to speak on the more intimate aspects of parenting. We will meet children over 2 years who continue with breast milk, or sleep with their parents despite having their own room, or perhaps consider that there are no behaviour limits, etc. Regardless of our opinions, we must refrain from criticism and unwanted advice, because it will damage the relationship of trust.

The first thing is to show respect and confidence about the parenting situation. We cannot forget that the family wants the best for the child and has its own reasons for its decisions. From that place we can ask and know the causes. It is that moment of understanding which further solidifies the association, and we professionals may get a different perspective once we understand better.

We can jointly analyse how the situation is benefiting the child and how it can be improved. It is at this point that the family usually changes its perceptions. So we can draw conclusions about what things benefit the child and how can we achieve them. Walking together is easier.

This way of working can also be applied to classroom groups, whether we are teachers, educators, assistants, guidance counselors, etc. Respect, understanding and patience are ingredients that improve all aspects of life.

Sometimes I take the "uncooperative families” as a challenge. I have found that when I find the bond with the family, everything flows and the child gets started.

My last recommendation: if we don't achieve an appropriate association with a family, arranging to have them work with a different professional might be a solution. In conclusion, and to my regret, I have observed that "professionalisation" has proliferated at the expense of the human touch in our occupation. Let us redirect it as we can.

Support Network for Professionals in Early Intervention for Children with Visual Impairment and their Families

DATO Group, National Organisation of the Spanish Blind (ONCE), Spain
grupodato@once.es

The National Organisation of the Spanish Blind (ONCE) has a long tradition in Early Intervention (EI) with children aged 0 to 6 who are visually impaired and their families.

Within ONCE's 23 education teams, composed of professionals of ONCE and the local administration, there are some professionals who work with children below the age of six and their families. These teams are coordinated from 5 Educational Resource Centers (CREs), which also provide resources and services to children and training to professionals.

The CREs have offered professional early intervention training for many years. Within the past decade, a permanent seminar on early intervention has been formed in each Resource Centre, comprising professionals of all the teams that depend on that CRE.

However, the large number of full- and part-time early intervention professionals were making it difficult to identify and coordinate activities at a global level, communicate what was done in each CRE, provide the appropriate training, and share good practices.

Therefore, in the year 2011, ONCE created DATO Group, a working group for the revitalisation of early intervention activities throughout Spain.

There is a central task force composed of three professionals. One professional in the seminar in each of the five CREs serves as the link with the task force, sharing information in both directions. The aim of DATO Group is to support and coordinate the many early intervention activities developed by the Specific Educative Teams. They start with communicating about them, and DATO Group serves to transmit and share existing information and best practices.

Since DATO Group's creation, it has accomplished a number of things:

- Preparation and publication of a base document on early intervention that establishes the essential criteria of services to children and their families. It describes the concept of EI and defines the objectives, principles, target groups and stages. It also sets up the general criteria of services, professional profiles and coordination between them, as well as the most appropriate teaching resources and assessment tools for this population.

- Publication of a monograph on early intervention in *Integración* (Atención temprano, 2011), a journal for visual impairment, published by ONCE (Number 58, September-December 2010). In this monograph are more than 20 articles and best practices about various aspects of child development and assessment, emotional development, families and social work, the use of ICT, experiences of professionals from all around Spain, and testimonials from students, families and teachers of nursery schools.
- Design, development and dissemination of an information leaflet called "Early intervention, blindness and visual impairment: A service of ONCE", with the aim of promoting the detection of infants and children with visual disabilities. The leaflet is written in nonclinical language for parents, explaining the symptoms that families must be attentive to, and the services available to their children and themselves. It was published in 2015 and has been distributed to the general teams of early intervention, ophthalmologists, pediatricians, and other services where families may attend with a visually impaired child.
- Permanent contact with the seminar of each Educational Resource Center. As we said before, in each Seminar there is a liaison figure between DATO Group and the professionals who quarterly attend it. With these laison professionals there is an ongoing relationship, with two-way information about courses, conferences, and other matters of interest. They are also responsible for mobilising professionals in their areas. For instance, for this issue of *The Educator* we have received six articles written by early intervention professionals from different parts of Spain.

In November of 2016, there will be a meeting of all professionals that make up the five seminars of early intervention. In addition to a panel discussion with experts, there will be ten reflection groups, about various topics proposed by the seminars themselves, and some sessions to share experiences of all attendees. Among the topics proposed by the seminars are the role of professionals, intervention models based on families, parenting guidelines, the experience of the body, multiple disabilities, and more. These are issues of common interest to most professionals working with children from 0 to 6 years. From these discussion groups we will draw up conclusions that hopefully will serve to improve training and services.

DATO Group also collaborates with ICEVI Europe, coordinating the interest group on early intervention. The first action taken in this regard has been the development and analysis of a European survey on early intervention services, and the consequent report about it. Although only a few countries participated in the survey, we have obtained very interesting data. There are some points of agreement about the importance given to early intervention and its preventive nature, the involvement with both children and their families, and the

need for specific training. However, the work lines differ from one country to another: in some of them the priority is the attention to children; in others the priority are the families; the starting age of schooling is different in each country; professional profiles involved also differed from one country to another, etc.

In addition to these findings, we have made a series of recommendations for ICEVI Europe, which are also serving as a basis for joint work with the European Blind Union. Among the recommendations from that report, we highlight the need for awareness of governments and institutions to ensure care and attention for children with visual impairment under 6 years and their families, the creation of minimum standards of service, and professional training. Moreover, from the European group of Early intervention we are trying to organise a group of interest within the website of ICEVI Europe and want to organise a small European Seminar to formally set up the European Task Force on Early Childhood.

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Participating Countries

