10th World Down Syndrome Congress

Dublin City University, Dublin, Ireland

19th – 22nd August 2009

LIFELONG LIVING AND LEARNING

Bringing together the international Down Syndrome Community

ABSTRACTS AND PROCEEDINGS

World Down Syndrome Congress 2009

DUBLIN • IRELAND

Local Organising Committee

Pat Clarke (Chair)

Margaret Carroll, Caroline Casey, Richard Connolly, May Gannon, Grainne Murphy, Ingrid Murphy, Dr Joan Murphy, Mary O'Reilly, Christina Riordan, Penny Robertson, Vanessa Dos Santos

Scientific Committee

Professor Hilary Hoey (Chair)

Professor Sue Buckley, Dr Jacob Burack, Dr Joan Murphy (Hon Secretary), Professor Juan Perera, Professor David Patterson, Dr Dan Weeks, Mr Pat Clarke, Mrs Penny Robertson

DSInternational Advisory Committee

Kitt Boel, Professor Roy Brown, Dr Jacob Burack, Pat Clarke (Vice-President), Assoc-Prof. Monica Cuskelly, Marja Hodes, Dawn McKenna (Treasurer), Dr Eiichi Momotani, Professor David Patterson, Rehka Ramachandra, Penny Robertson (President), Vanessa Dos Santos (Secretary), Dr Balbir Singh, Bridget Snedden, Dr Dan Weeks, Paul Zanon (Company Secretary)

Host Organisation

Down Syndrome Ireland
City Link Business Park
Old Naas Road
Dublin 12
Tel: +353 1 4266500
Fax: +353 1 4266501
E-Mail info@downsyndrome.ie
Web www.downsyndrome.ie

Congress Secretariat

Keynote PCO
26 Anglesea House
63 Carysfort Avenue
Blackrock
Co Dublin
Tel: +353 1 4003626
Fax +353 1 4003692
E-mail downsyndrome@keynotepco.ie
Web www.keynotepco.ie

World Down Syndrome Congress 2009
DUBLIN • IRELAND

Hosted by

Down Syndrome Ireland

DSI Down Syndrome International

edsa EUROPEAN DOWN SYNDROME ASSOCIATION

iassid International Association for the Scientific Study of Intellectual Disabilities

DSQ Down Syndrome Quarterly

downsed™ discovering potential • transforming lives www.downsed.org

We are very grateful to all the members of the Scientific Committee for their help and support with the Scientific Programme and to Ms Christina Riordan, Office Manager, and the office team, Down Syndrome Ireland, for their invaluable help and administrative assistance

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CONGRESS CHAIR & PRESIDENT OF DOWN SYNDROME IRELAND's MESSAGE

Dear Participants,

On behalf of Down Syndrome Ireland and Down Syndrome International we wish to welcome you to Dublin, Ireland and Dublin City University for the 10th World Down Syndrome Congress.

We have an innovative and educational programme planned for everyone – people with Down syndrome, parents, carers and professionals. The programme is very full which will keep you occupied to the fullest extent but I do hope you will find time to renew old acquaintances and to make new friends during the breaks and social events.

We wish to acknowledge the hard work of the organising and scientific committees who have given of their time and energy over the past three years. We wish to thank the members and the branches of Down Syndrome Ireland who have joined us enthusiastically in making this congress the success I know it will be. We also wish to thank the international advisory committee that is the board of Down Syndrome International for their support and advice

Thank you, the delegates for joining and supporting us in these recessionary times when we know that resources are tight and that there are other pressing calls for these scarce resources. We hope that you are stimulated, informed and inspired by the presentations, workshops etc and that you will view your time here in Dublin this August as time well spent.

We look forward to greeting all of you at the congress and we trust that you will bring much knowledge and many happy memories from your time in Dublin.

With kind regards,

Mary O'Reilly

President,

Down Syndrome Ireland

Pat Clarke

Chairperson, 10th World Down Syndrome Congress

Down Syndrome Ireland

DSINTERNATIONAL PRESIDENT'S MESSAGE

Dear delegates & guests,

It gives me great satisfaction and pleasure to be able to welcome you to the 10th World Down Syndrome Congress in Dublin. This congress marks the coming of age of DSI as we celebrate our 10th World Congress, which is made all the more significant because it marks the 50th anniversary of the publication of Professor Jerome Lejeune's discovery of the extra copy of chromosome 21 which identifies people with Down Syndrome which we know eponymously as trisomy-21.

It has been really encouraging to see the number of people from so many different countries have contacted us to seek information about the congress. The world has certainly grown smaller! While current economic conditions have not allowed everyone who wished to attend to do so the huge response which we have had to the conference is very encouraging.

I congratulate Pat Clarke, Professor Hoey, Dr. Joan Murphy and Mary O'Reilly and their team in putting together an exciting program with tremendous international interest. A record number of abstracts have been received.

I also acknowledge the great encouragement and financial support from a range of Government bodies, academic institutions and commercial enterprises in order to support us in hosting this congress which will greatly benefit people with Down syndrome and those caring for them.

The initiative of holding the first International Synod of people with Down syndrome on the 19th August in association with the Congress itself will give adults and young people with Down syndrome an opportunity to meet their peers from across the globe and to discuss issues that affect their lives.

This congress should be a rewarding congress for you all. It will equip you with new and useful information and provide you with the means to add richness to the lives of persons with Down syndrome and the communities in which they live.

After a wonderfully successful conference in Vancouver in 2006, expectations are very high for Dublin and I know that you will not be disappointed. I look forward to meeting you and exchanging ideas. DSI's wonderful team of advisors will be available to meet with you at the DSI stand throughout the congress and to discuss your individual experiences and challenges.

The DSI Board of Directors would like to express their appreciation to all sponsors, delegates, presenters, volunteers and members of the various committees for making the WDSC10 a memorable and successful conference.

We look forward to meeting you again in Cape town, South Africa in 2012 for the 11th Down Syndrome congress. It promises to be another great Congress under the able leadership of Vanessa dos Santos. Make sure that you catch up with Vanessa at the DSI stand and start making plans to attend our first African Congress and prepare yourself to experience South African hospitality at its best.

Penny Robertson, O.A.M

President

Down Syndrome International

August, 2009

DSI Down Syndrome International

Down Syndrome International Report of Activities 2006-2009

International Collaborations

In 2006 DSI held many discussions around the mission statement and goals for the future of the organisation. It resolved that Down Syndrome International exists to advance the interest of individuals with Down syndrome and those involved in their care, education, and support throughout the world. The primary vehicle by which DSI would achieve this goal would include facilitating World Down Syndrome Day, the world congress,the development of infrastructure and support for developing countries, supporting on site assessment of specific infrastructural, organisational and attitudinal needs by teams of specialists.

Membership

The membership of DSI has grown considerably since the introduction of World Down Syndrome Day and a decision was taken by the Board to offer affiliate membership to countries which have had difficulty paying the membership fees but which nevertheless need DSI's services. The goal in this case being to build up a worldwide membership of DSI.

The Board noted the need to further develop the standing orders on memberships and voting rights as the organisation grows, as allowed for in the Constitution.In compliance with DSI Board regulations and our UK Charity Commission guidelines, Board members who have not participated in three successive meetings of DSI forfeit their position on the Board.

DSI Board

DSI Board members are: Kitt Boel (Denmark), Prof. Roy Brown (Canada), Dr. Jacob Burack (Canada), Pat Clarke ((Ireland), Vice-President), Assoc-Prof. Monica Cuskelly (Australia), Marja Hodes (Netherlands), Dawn McKenna ((Canada)Treasurer), Dr. Eiichi Momotani (Japan), Prof. David Patterson (U.S.A.), Rehka Ramachandra (India), Penny Robertson ((Indonesia) President), Vanessa dos Santos ((South Africa) Secretary), Dr. Balbir Singh (Singapore), Bridget Snedden (New Zealand), Dr. Daniel Weeks (Canada), and Paul Zanon ((U.K.) Company Secretary).

Advisory Board

DSI is honoured to have Dr Janet Carr, Prof Cliff Cunningham, Prof Sylvia Garcìa-Escamilla, Prof David Patterson, Prof Juan Perera, Prof Siegfried Pueschel and Mr Ramachandra join us as advisors.

World Congresses

The need for support for less developed countries was recognised during the Singapore Congress and the congress organisers utilised the international expertise attending the Congress by having the Hospital host a medical conference in conjunction with the Congress. Since this initiative, a medical interest group has held a conference prior to each of the congresses.

Bids for the next Congress were called for and the 11th world Down Syndrome Congress was granted to Cape Town, South Africa for 2012 following an excellent presentation by Vanessa Dos Santos.

World Down Syndrome Day (WDSD)

Following DSI's decision to nominate 21st March as World Down Syndrome Day there has been a tremendous increase in the awareness of Down syndrome worldwide and in the number of countries participating. The number of events which have been held to celebrate the day has increased dramatically in every country. The WDSD website was initially hosted

by the Singapore DS association and to them I extend my thanks. This website will be incorporated into the DSI website in the near future.

There has been a 300 fold increase in the number of website hits during March and April this year. Many emails from countries where there are no services have been received since the inception of WDSD. The UN has not yet recognised this day but moves to secure UN recognition are in progress.

2009 represents 50 years since Prof. Lejeune identified the 47th chromosome as the ultimate cause of Down syndrome. A press statement was released and put on the DSI website to commemorate this event.

DSI Website:

I would like to pass my sincere thanks to the Down Syndrome Research Foundation of Canada for the development and management of the DSI website (http://www.ds-int.org). In particular I extend my thanks to Dave Kisley for his understanding and patience in tutoring board members on its use. Profiles of board members are now online as are the record of the past year and the location of each congress to date.

We recognise the importance of the website as our major means of communication and we are in the process of redesigning it to properly reflect the role DSI plays as a clearing house, rather than the provider, of information and services. In order to do this effectively we need active participation from all countries and organisations to keep their own information current and up to date.

Down Syndrome Journal

Dr. Jacob Burack joined the DSI Board in his role as editor of the Down Syndrome Quarterly. DSQ will set aside a special issue to cover the papers presented at the upcoming Dublin World congress.

Outreach programs

Outreach programs are designed to bring expertise and awareness of intervention programs to countries which need our support.

DSI has successfully completed its first outreach program in Libya with the financial support of the Libya BG Group in 2007 and 2008. DSI donated volunteer services of four board members and two non-board members. This program was self funded and brought in much needed finances for DSI while providing high profile expertise and advice to the Libyan DS Association.

It should prove a successful model for future outreach programs. An initial visit undertook an evaluation of services on offer and plans for future workshops and this was followed up in May this year by a visit by five professionals covering the areas of human rights, education, employment, speech therapy, occupational therapy and fundraising.

Collaboration

Closer collaboration has occurred with organisations such as the World Health Organisation (when Dr Balbir Singh and I attended their conference in Bangkok), the United Nations (when Dr Dan Weeks and I attending the signing of the United Nations Declaration of Human Rights in New York), Inclusion International (when Vanessa dos Santos attended their conference in Mexico) and IASSID (with whom we have an cooperation agreement).

The IASSID Council and Down Syndrome International (DSI) have signed an agreement to facilitate co-operation and mutual support. Under this agreement a Special Interest Research Group (SIRG) is proposed. The SIRG is a means of drawing DSI and IASSID together to promote research and practice and I wish to acknowledge the tremendous efforts by Prof Roy Brown in promoting the work in this area. Meetings of this group have taken place in Capetown and most recently in Singapore.

International Scientific Advisory Committee

We have set up of the International Scientific Advisory Committee (SAC) steering committee (David Patterson, Monica Cuskelly, Cliff Cunningham, Rhonda Faragher, Dan Weeks, Jake Burack and Roy Brown) to define the role of the SAC and to set an international research agenda which will be of the greatest value to people with Down syndrome.

We will continue to formalise links with other research groups, academies, etc which disseminate research and practice on an international basis.

Policy Statements

Board members developed a Position Statement on Pre-natal Screening, which is published on our website. The Board will continue to formulate occasional papers on key social and medical issues such as screening as required.

DSI Secretariat

The need to set up a proper secretariat for DSI has been an ongoing issue for some time and with the assistance of the DSA UK office, DSI has been offered space and some logistical support at the offices of DSA UK at John Langdon Down House, Teddington, UK. As this was the original home of John Langdon Down it seems most appropriate that we situate our permanent headquarters there. I thank the DSA UK Board for the assistance that they have offered DSI and I look forward to a more permanent arrangement under which the keeping of all minutes, membership, project and financial records for DSI can be centralised at John Langdon Down House; and to a time when DSI will have sufficient full time staff to more adequately promote and advance the work of DSI throughout the world.

Penny Robertson O.A.M.

President

August, 2009

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CONTENTS

WDSC 2009 PROGRAMME WITH PLENARY SPEAKERS

Time	Wed 19/08/09	Thursday 20/08/2009	Friday 21/08/2009	Saturday 22/08/2009
07:00		Registration (Registration desk attended all day)	Registration (Registration desk attended all day)	Registration (Registration desk attended all day)
08:00		Registration	POSTER PRESENTATIONS	POSTER PRESENTATIONS
		Chair Mr Pat Clarke	Chair: Prof H Hoey / Prof S Pueschel	Chair: Prof Sue Buckley
8.45 to 10.30	DSMIGS DS RESEARCH DS SYNOD	LIFE POSSIBILITIES & ACHIEVING FULL POTENTIAL **8.45 Opening Address:** Pat Clarke President Elect DS International; Mary O'Reilly President DS Ireland; Penny Robertson President DS International **9.05 PRESIDENT OF IRELAND – OFFICIAL OPENING** **9.20 Life Possibilities-** May Gannon (Ireland) **9.45 Self Concept** - David Hingsburger (Canada) **10.00 Live Dance Presentation** - Echoes (Ireland)	PROMOTING GOOD HEALTH & WELL BEING **8.45 Good Health & Well Being -** Prof Hilary Hoey (Ireland) **9.00 Childhood -** Dr. Liz Marder (UK) **9.15 Adolescents** –Dr J Murphy (Ireland) **9.30 Nutrition & Lifestyles -** Joan Guthrie Medlen (USA) **9.45 Mental Wellness Adults & Ageing -** Dr Dennis McGuire (USA) **10.00 Sexuality -** David Hingsburger (Canada)	EFFECTIVE EDUCATION & INCLUSION **8.30 Benefits of Inclusion & Keys to Success** **Preschool / Primary /Secondary** - Dr Ursula Doherty (Ireland) **8.45 Encouraging Literacy at home and school** - Dr Gillian Bird (UK) **9.00 Encouraging Soc Inclusion & managing behavior** - Prof K Feeley (USA) **9.15 Transition / Adult ongoing Education** - Dr. P O'Brien (NZ & Ireland)
10.30–11.00		Refreshments POSTER PRESENTATIONS	POSTER PRESENTATIONS	9.45 - 10.15 Refreshments
		Chair: Prof Andrew Green / Dr Margaret Sheridan	Chair: Prof. Michael O'Keeffe / Mr Don McShane	Chair: Mr Christy Lynch / Dr Ian Daly
11.00-12.30	DSMIGS DS RESEARCH DS SYNOD	POSITIVE SUPPORT IN EARLY YEARS **11.00 Caring Doctors** - Prof Conor Ward (Ireland/UK) **11.15 Genetics** –Prof David Patterson (USA) **11.30 Lessons Learned & Family Needs -** Prof Juan Perera (Spain) **11.45 Early Intervention** - Dr Sheila Macken (Ireland) **12.00 Managing Life with Down Syndrome** - Cora Halder (Germany)	SUPPORTING BEST VISION,COMMUNICATION, LANGUAGE & LEARNING **11.00 Ensuring Best Possible Hearing** - Mr Patrick Sheehan (UK) **11.15 Promoting Clear Speech** - Dr Clothra Ni Cholmain (Ireland) **11.30 Supporting Language & Communication** - Prof Jean Rondal (Belg) **11.45 Ensuring Best Possible Vision** - Prof M Woodhouse (UK)	ENSURING GOOD QUALITY OF LIFE FOR ADULTS **10.15 Providing a range of Living options -** Prof Roy McConkey (N. Ireland) **10.30 Quality and Family Quality of Life for People with DS: Issues of adolescent and adult life -** Prof Roy Brown (Canada / AUS) **10.45 Independent Community Living -** Prof S Eidelman (USA) **11.00 Increasing Employment options -** Ms Anne O'Bryan (UK)
12.30 to 1.30pm		LUNCH POSTER PRESENTATIONS	LUNCH POSTER PRESENTATIONS	11.45 – 12.45 pm LUNCH
1.30-2.30pm		1.30 – 2.30 MEET THE EXPERTS	1.30 – 2.30 pm MEET THE EXPERTS	12.45-1.45 pm MEET THE EXPERTS
		Genetics; Early Intervention; Lessons Learned & Family Needs /Managing Life with DS; Life Possibilities; Self Concept	Child Health; Adolescent Health; Mental Wellness; Nutrition & Lifestyles; Hearing; Clear Speech & Language; Vision; Supporting Language & Communication; Sexuality	Inclusion in school; Encouraging Literacy; Teaching children to read; Social Inclusion & Managing Behaviour; Transition from School; Living Options; Application of QOL principles; Independent Community Living; Increasing Employment Options
2.30 – 3.00 pm		Refreshment	POSTER PRESENTATIONS	1.45-2.00 pm Refreshments
3.00 – 5.00pm	DSMIGS DS RESEARCH DS SYNOD (by Adults with Ds)	3.00 – 5.00 pm Expert Workshops & Oral Presentations Concurrent Sessions Early Development /Intervention; Education (1); Education (2); Health; Siblings & More; Physical Activity; Breaking news; Positive Behaviour; Moms Only; Grandparents; Mental Wellness; Parent Perceptions & Family Needs; Speech & Language/ Feeding	Health (1); Education (1); Quality of Life; Education (2); Friendships; Aging; Employment; Speech /Language & Feeding; Adult Living; Dads; Education (3); Independence/Transition from School; Health (2)	2.00 to 3.00 pm Inclusion and Interactions; Health; Early Intervention; Education 3.15 pm GENERAL ASSEMBLY A Tribute to Jo Mills – Penny Robertson (Indonesia) Jo Mill's Memorial Lecture 'International UN Rights of People with Disabilities By Prof Gerard Quinn (Ireland) DSI Report CLOSING CEREMONY
6.30pm	STATE RECEPTION Royal Hosp Kilmainham	Welcome Reception Live Dance Show (Counterbalance)	7.30 pm Impromptu Entertainment United by Music with Sujeet Desei	8.00 pm Gala Dinner with Performances

Programmes for children and adults with Down Syndrome to run in parallel with Scientific Programme

Thursday 20th August 2009

Plenary Lectures

Life Possibilities and Achieving Full Potential

Life Possibilities	May Gannon
Self Concept	David Hingsburger
Live dance presentation	Echoes

Positive Support in Early Years

Caring Doctors	Professor Conor Ward
Genetics	Professor David Patterson
Lessons Learned & Family Needs	Professor J Perera & Alex Snedden introduction
Early Intervention	Dr Sheila Macken
Managing Life with Down Syndrome	Ms Cora Halder

Meet the Expert

Genetics	Professor David Patterson
Early Intervention	Dr Sheila Macken
Lessons Learned & Family Needs & Managing Life & Down syndrome	Professor J Perera & Ms Cora Halder
Life Possibilities	Ms May Gannon & team
Self Concept	Mr David Hingsburger

Oral Presentations 3-5 pm

Early Development/Intervention

The role of parents in early intervention	Professor Gerald Mahoney, USA
Early Engagement & Communication	Dr Mari Caulfield, Galway
The effect of Educational and Psychological Family-centred early intervention on the Developmental Performance of Children with Down syndrome	Salar Faramarzi, Iran
Early Intervention Services	Mrs Parvathy Viswanath, India
Learning to Move	Dr Susana Martins, Portugal

Education (1)

Re-writing the Data on Down Syndrome	Ms Karen Gaffney, Self Advocate, USA
Inclusive Education at the Post-secondary Level in Western Canada - A Review	Professor Michael Shaw, Canada

Oral Presentations 3-5 pm

Thursday 20th August 2009

Education (1) cont'd

Inclusive Post-Secondary Education: A promising path to an inclusive life	Mr Bruce Uditsky, Canada
Nourishing the Spirit of People with Down Syndrome	Dr. Ian Dickson, Northern Ireland
EU Project MOTE (My Opinion, My Vote) Project	Dr Paola Vulterini and European colleagues

Education (2)

Learn to Read to Support Language Program - Promoting speech, language and literacy	Ms Teresa Condeco, Portugal
Teachers' perspectives on the application of the Handwriting Without Tears® (HWT) programme with children with Down Syndrome in an Irish context	Dr Sandra Patton, Ireland
Exploring the Effectiveness of Phonics-Based Instruction for Children with Down Syndrome	Dr Chris Lemons, USA
Teaching Reading to Individuals with Down Syndrome	Ms Denise MacDonald, Canada
Creating Literacy: Young Children with Down Syndrome and Typically Developing Children Constructing Meaning Together in Inclusive Classrooms	Professor Chris Kliewer, USA
Introducing an intervention to improve reading and language outcomes for children with Down syndrome in mainstream classrooms	Kelly Burgoyne, Sue Buckley, Maggie Snowling and Charles Hulme, UK

Health

Families & Professionals: What Really Matters II	Dr Xavier Lopez-Oliver, Spain
Improvising Disability with Music	Dr Sindoor Desai, USA
Iron Deficiency and Down Syndrome	Ms Lynn Rastelli, Canada
Issues in Latex allergy in Children and Adults Receiving Home Healthcare	Ms Maureen Gavin, USA
Happy Strap	Mrs Janet Wichmann, South Africa

Siblings and More

Adult siblings: early contributors to relationships	Professor Monica Cuskelly, Australia
Informing Children of Their Sibling's Diagnosis of Down Syndrome	Dr Marcia Van Riper, USA
Siblings of Children with Down Syndrome	Professor Etta Wilken, Germany
The Mexican School of Down Art	Ms Sylvia G. Escamilla, Mexico
Highlights of Mexican Down Art	Ms Sylvia G. Escamilla, Mexico

Thursday 20th August 2009

Oral Presentations 3-5 pm

Physical Activity

Identifying Facilitators and Barriers to Physical Activity for Adults with Down Syndrome	Dr Nora Shields, Australia
The Level of Physical Activity in Irish Children with Down Syndrome	Dr Nora Shields, Australia
Treadmill Training and Infants with Down Syndrome: Results and Procedures	Professor Dale Ulrich, USA
Skinny Alympiks...Fighting Obesity Among People With Intellectual Disability	Mrs Vicki Brown, Australia
Can We Teach Youth with Down syndrome to Ride a Two Wheel Bicycle? Yes we can	Professor Dale Ulrich, USA

Breaking news

The Importance of Fair and Balanced Information in the Prenatal Setting	Ms Krista Flint, Canada
Informing Parents of their baby's diagnosis of Down's Syndrome - How are we doing?	Dr Patricia Jackson, Scotland
Prenatal Testing, Down Syndrome, & What To Do For Future Generations	Mr Mark Leach, USA
Family Leadership	Mrs Annette Mayer, Australia
Reproductive Decision-making in Families of Children with Down Syndrome	Dr Marcia Van Riper, USA

Positive Behaviour

Developmental and Behavioural disorders in people with Down Syndrome aged 8-18 years	Dr Miguel Palha, Portugal
Behavior problems and maternal mental health problems & children with DS, autistic children, non-intellectually disabled and other intellectually disabled children	Assoc Professor Mojtaba Amirimajd, Iran
Building on Family Strength and Resilience - A Practitioner Review	Dr Grania Clarke, Ireland
Fathers of children with Down syndrome - A Research Study	Dr Elaine MacDonald, Ireland
Autistic Spectrum Disorders in Down syndrome	Dr Colin Reilly, Ireland
The Changing Nature Of Support Across The Life Cycle: Learning From Research; Learning From Practice	Dr Grania Clarke, Elaine MacDonald, Colin Reilly, Ireland

Oral Presentations 3-5 pm

Thursday 20th August 2009

Moms/Grandparents

Moms only workshop	Mrs May Gannon, Dr Mercedes Egan & Mrs Annete Mayers
Grandparents only workshop	Pascale Claes

Mental Wellness

Social and Emotional Development of Young People with Down Syndrome	Professor Trevor Parmenter, Australia
'Self-talk' - what's it all about?	Ms Judy Opolski, Australia
Self-talk in children and adults with Down syndrome	Mr Paul Patti, USA
Down Syndrome in Association with Mental and Physical Illness – Adam's Story	Mrs Pauline Stewart, Spain
The Physical and Mental health in Mothers of Children with Down syndrome - What makes a difference?	Mrs Jenny Bourke, Australia
The prevalence of Attention Deficit/Hyperactivity Disorder (ADHD/ADD) among children with Down syndrome	Dr Ariel Tenenbaum, Jerusalem

Parent Perceptions & Family Needs

A Journey of Life and Independence	Mr & Mrs Graham and Annette Mayer, Australia
Down Syndrome NOW Research Lessons we have learned as parents involved in research	Ms Jackie Softly, Australia
The Value of Parent to Parent Support	Sue Robins and Mike Waddingham, Canada
Parents of Children with Down Syndrome (POD)	Mrs Liana Vislan, Romania
Down Syndrome School Behaviour Clinic	Dr Philip Mattheis, USA

Speech & Language/ Feeding

Facilitating speech and language therapists in training through a real life case	Ms Clare O'Shaughnessey, Galway
A National Strategy for the Development and Delivery of speech language and communication services: Increasing provision through the co-worker network and other initiatives	Ms Leela Baksi, UK
Targeting speech, language and literacy development in the early years	Ms Julie Hughes, UK
Analysis of Two Early Language and Literacy Programs for Young Children with Down Syndrome a Pilot Study	Dr Karen Riley and Dr Gloria Miller, USA
Solution Focussed Brief approach to target setting - Sharing experience of working together with parents of children with Down Syndrome	Mrs Gillian Flanagan, UK

Friday 21st August 2009

Plenary Lectures

Promoting Good Health & Well Being

Good Health & Well-Being	Professor Hilary Hoey
Child Health	Dr Liz Marder
Adolescent Health	Dr J Murphy & Emanuel Bishop introduction
Nutrition & Lifestyle	Joan Guthrie Medlen
Mental Wellness Adults & Ageing	Dr Dennis McGuire
Sexuality	David Hingsburger

Supporting Best Vision, Communication, Language and Learning

Ensuring Best Possible Hearing	Mr Patrick Sheehan
Promoting Clear Speech	Dr Clothra Ní Cholmain
Supporting Language & Communication	Professor Jean Rondal
Ensuring Best Possible Vision	Professor M Woodhouse

Meet the Expert

Child Health	Dr Liz Marder with Dr Sheila Puri, Dr Monica Pinto
Adolescent Health	Dr Joan Murphy with Professor Siegfried Pueschel, Professor Trevor Parmenter and Dr. Nora Shields
Mental Wellness	Dr Dennis McGuire
Nutrition & Lifestyles	Ms Joan Guthrie Medlen
Hearing	Mr Patrick Sheehan
Clear Speech & Language	Dr Clothra Ni Cholmain and Dr Aine Kelly
Vision	Professor Margaret Woodhouse
Supporting Language & Communication	Professor Jean Rondal
Sexuality	David Hingsburger

Oral Presentations

Friday 21st August 2009

Health (1)

Chronic constipation due to dolichosigmoid (sigma elongatum) in children with Down Syndrome	Dr Wolfgang Storm, Germany
The role of chlorhexidine in the management of periodontal health in people with Down syndrome	Professor June Nunn, Dublin
The Metabolic Syndrome characteristics in Down Syndrome	Dr Ariel Tenenbaum, Israel
Congenital heart disease in children with Down syndrome	Assoc Professor Myrvete Kelmendi, Albania
Understanding the impact of puberty and menstruation on females with Down syndrome	Dr Margaret Kyrkou, Australia
Effects of rapid maxillary expansion in Down Syndrome	Dr David Andrade, Portugal

Education (1)

My Story	Sujeet Desai, USA
Down syndrome and automatic processing of emotional facial information	MC Guadalupe Morales, Mexico
Perceptions of parents and speech and language therapists on mainstream primary education	Siobhan Keohane and Ciara Skehan and Clare O'Shaughnessy, Galway
Parents' Perspectives on the Application of the Handwriting Without Tears (HWT) programme with children with Down Syndrome in an Irish context	Dr Sandra Patton, Dublin
Special Education in Our Schools Through an Inclusive Lens	Dr Ashleigh Molloy, Canada

Quality of Life

To Go Boldly	Mr Alex Snedden, New Zealand
Quality of Life and Quality of Care of People with Down Syndrome	Assoc Professor Dagmar Dzurova, Czech Republic
Locked Away and Safe or Living Large in Berkeley, CA	Ms Kathryn Edwards, USA
Translating Quality of Life into Service Action: Use of Personal Outcome Measures in Ireland	Dr Margaret Farrell, Ireland

Education (2)

More academics in regular school?	Mr Gert de Graaf, Netherlands
Accommodations and Modifications for Including Students with Intellectual Disability into the Mainstream Classroom	Ms Mary Frances Edwards, Ireland

Friday 21st August 2009

Oral Presentations

Education (2) cont'd

Mastering the art of Multi-level teaching...the key to life long learning	Mrs Azette Engelbrecht, South Africa
Inclusion vs Integration	Mr Bryan Harman, Canada
Individualized Academic Intervention for Adults with Down Syndrome: Assessing Progress over Time	Professor Melissa Rowe, USA

Friendship

Powerpoint Presentation 'Before and After' with Violin Recital	Emmanuel Bishop (Age 12), USA
'A friend in need...' the challenges of friendships for adolescents and young adults with Intellectual Disability who live in rural Tasmania	Ms Helen Zournazis, Australia
Fighting Isolation	Mr Driton Bajraktar, Republic of Kosova
"Stepping in Cinderella's shoes", a young girl's quest for identity and empowerment	Esther Joosa, Singapore
The Rarely Heard Voice	Dr Michael O'Keeffe, Ireland

Aging

A Multicenter Vitamin E Trial in Aging Persons with Down syndrome: Progress Report	Dr Arthur Dalton, USA
Relationship between Amyloid β (Aβ) Protein and immune inflammatory markers in Down Syndrome	Dr Pankaj D. Mehta, USA
Cost and Quality of Life in Service Delivery for Persons with the dual disability of Down Syndrome (DS) Alzheimer's Dementia (AD)	Professor Mary McCarron, Dublin
Understanding the onset of dementia symptoms	Professor Mary McCarron, Dublin
Maintaining Health and independence in older years	Professor Philip McCallion, USA
Life Events, Relocation and End of Life Issues in Aging Adults with and without Down Syndrome	Dr Paul Patti, USA

Employment

Reach for your Dreams and Celebrate Abilities: Self Employment Works for me	Dylan Kuehl, USA
Fostering Personal Autonomy and Full Self-Awareness	Anna Contardi, Italy
Towards full social participation	Mrs Cecile Dupas and a group of 4 adults, France

Oral Presentations

Friday 21st August 2009

Employment cont'd

"Young and Enthusiastic" ICT-Based IADL training	Dr Gro Marit Roedevand, Norway
DownWho? The Image of people with DS in Italy	Anna Contardi, Italy

Speech and Language and Feeding

The use of Lamh and children with Down syndrome: Parents' views	Ms Clare O'Shaughnessy, Ireland
The Links between Signing and Talking	Professor Sue Buckley, UK

Adult Living

Adults Living Adult Lives	Professor Roy Brown, Canada

Dads

Father & Son, My Story	Mr Thomas & Bryan Lambke, USA
Dads Appreciating Down Syndrome	Stephen Simpson, USA
Dads Appreciating Disabilities International	Mr Graham Mayer, Australia, & Ray Murray, Ireland
Dads Only	Mr Graham Mayer, Australia, & Ray Murray, Ireland

Education (3)

Maths and me! Learning about mathematical development by listening to young children with Down syndrome	Ms Rhonda Faragher, Australia
Maths is easy	Mag Bernadette Wieser, Austria
Maths and Money	Ms Anne Squire, Australia
Number Skills Intervention Program	Teresa Condeco, Portugal
Learning Mathematics in mainstream secondary schools: the experiences of Francesca and Martina, two students with Down syndrome	Dr Elizabeth Monari Martinez, Italy

Independence/Transition from School

Stepping Stones to University	Ms Rachel High, Australia
The way to empowerment of people with Down Syndrome towards an independent lifestyle: lessons learned from Escuelas de Vida (Schools of Life) and Viviendas Compartidas (Shared Apartments)	Pedro Otón Hernández & Nuria Illán Romeu, Spain

Friday 21st August 2009

Oral Presentations

Independence/Transition from School cont'd

Making a Connection - The Impact of a Mentoring Program for Adults with Down Syndrome	Ms Catherine McAlpine, Australia
The Symbol Academy Showcase!	Ms Leela Baksi, UK

Health (2)

The Influence of Apolipoprotein E Genotype on the Age of Onset and Duration of Dementia in Individuals with Down Syndrome	Dr Niamh Mulryan, Dublin
An Audit of Health Service Provision for Children with Down's Syndrome in the U.K	Ms Elizabeth Layden and Dr Patricia Jackson, UK
Is early onset of osteoporosis in women and men with Down syndrome based on different factors?	Professor Maria Sustrova, Slovakia
Regression in young adolescents with Down Syndrome	Dr Deirdre Cahalane, Dublin
Sleep disturbances as a tool for early intervention against cognitive impairment in children and adults with Down syndrome	Professor Jacqueline London, France

Saturday 22nd August 2009

Plenary Lectures

Effective Education and Inclusion

Benefits of Inclusion & Keys to Success Preschool/ Primary/Secondary	Dr Ursula Doherty
Encouraging Literacy at home and school	Gillian Bird
Encouraging Social Inclusion & managing behaviour	Professor Kathleen Feeley
Transition from School / Adult ongoing Education	Dr. Patricia O'Brien

Ensuring Good Quality Of Life For Adults

Providing a range of living options	Professor Roy McConkey
Quality & Family Quality of Life for People with Down Syndrome: Issues of adolescent and adult life	Professor Roy Brown
Independent Community Living	Professor Steve Eidelman
Increasing Employment options	Ms Anne O'Bryan

Meet the Expert

Inclusion	Dr Ursula Doherty & Margaret Egan
Encouraging Literacy	Gillian Bird
Teaching Children to Read	Professor Sue Buckley with Ms Karen Gaffney introduction
Social Inclusion & Managing Behaviour	Professor Kathleen Feeley
Transition - Adult ongoing Education	Dr Patricia O'Brien
Living Options	Professor Roy McConkey
The application of Quality of Life	Professor Roy Brown
Independent Community Living	Professor Steve Eidelman
Increasing Employment Options	Ms Anne O'Bryan

Oral Presentations

Inclusion and Interactions

Inclusion as Easy as a Day at the Beach: The Camp PALS One-to-One Model	Mr Josh Stein, USA
Parental Perspectives on an Innovative Summer School	Mr Andy Loebus, Canada

Saturday 22nd August 2009

Oral Presentations

Health

Down Syndrome, cognitive function and aging	Professor Jacqueline London, France
Age Related Health Patterns among People with Down Syndrome in Europe	Dr D. Ryan, Ireland
Moving on from the Medical Model of Down syndrome	Ms Rhonda Grant, Canada

Early Intervention

The Responsive Teaching Curriculum	Professor Gerald Mahoney, USA
Education for a lifelong smile	Professor Martine Hennequin, France
Supporting social communication - is autism being over-diagnosed?	Professor Sue Buckley, UK

Education

Transition - a story of success	Ally Attwell & Debbie Rickard, New Zealand
Modern Approach to Child Inclusion in Russia: from parents initiative to professional care for children with Down syndrome	Ms Natalia Riguina, Russia
Peer interaction in mainstream classes	Ms Anne-Stine Dolva, Norway

Health

P1	Down Syndrome and Immune Abnormalities	Ms Lyne Tremblay, Canada
P2	Adults with Down syndrome are at reduced risk of cutaneous melanoma: results from a French study	Dr Daniel Satge, France
P3	Thyroid disease in Down's syndrome children: TSH screening in Scotland using dried blood spot samples 1997-2007	Dr Jeremy Jones, Scotland
P4	Neurodevelopment Impact of Congenital Heart Defects in Down Syndrome	Dr Jeannie Visootsak, USA
P5	"Doctor, my child's turned orange!" - A case series of hypercarotenaemia in children with Down's Syndrome	Dr Katherine Martin, UK
P6	Is Fatty Acid intake and metabolism in children with Down's Syndrome different when compared to their non-affected siblings?	Mrs Nina Brierley, UK
P7	Disclosure of the diagnosis of Down syndrome	Lynn Rastelli, Canada
P8	Diagnosis communication	Dr Carlo Baccichetti, Italy
P9	Diagnostic Overshadowing: The role of the multidisciplinary team	Ms Donna Heerensperger, Canada
P10	The Medical Diagnostic Challenge of Trisomy 21	Dr Sheila Puri, UK
P11	Education program in Sweden for healthcare professionals	Mrs Pia Enestram, Sweden
P12	Down Syndrome Health concerns in Kuwait	Dr Sadika Alawadi, Kuwait
P13	Thyroid Function in Down Syndrome - case review of a Portuguese Paediatric Hospital	Dr Monica Pinto, Portugal
P14	The Age Distribution of Onset of Celiac Disease	Dr Mary Pothos, Canada
P15	Alopecia areata in children with Down syndrome	Dr Wolfgang Storm, Germany
P16	Prevalence of Malocclusion in a Sample of Mexican School Children and Adolescents with Down Syndrome	Dr Patricia Lopez-Morales, Mexico
P17	Management of reflux and constipation: should we recommend activities to address posture and tone and promote core stability?	Ms Leela Baski, UK
P18	Growth in children with Down's syndrome and heart malformations	Dr Tilman Rohrer, Germany
P19	Survey on Gastrointestinal Issues in Children and Adults with Down Syndrome	Ms Maureen Gavin, USA
P20	Considerations on Undescended Testes in Children with Down syndrome	Dr Wolfgang Storm, Germany
P21	Achondroplasia and Down Syndrome - a case report of a rare association	Dr Sandra Santos, Portugal.
P22	Health problems in a group of 143 adults with Down syndrome in France	Dr De Freminville Benedicte, France
P23	Comprehensive Intervention in People with Down Syndrome	Dr Miguel Palha, Portugal

Health cont'd

P24	Optical quality is implicated in the poor visual performance in Down syndrome: Comparing different measurements of visual acuity	JA Little & JM Woodhouse et al, Ireland & UK
P25	Oral Health Promotion – Working Together – The Way Forward	Dr Maura Cuffe, Ireland

Early Development

P26	Down syndrome and automatic processing of emotional facial information: implications for their social life	MC Guadalupe Morales & Ernesto Lopez, Mexico
P27	Integration of People with Disability Experiences in Down Syndrome	Professor Maria Sustrova, Slovakia
P28	The Early Support of Basic Linguistic Competences and Communication Skills	Professor Etta Wilken, Germany
P29	"Precomunication Program" – promoting the early communication skills of children with T21, in the first year of life	Ms Teresa Condeco, Portugal

Demographics

P30	Down Syndrome in the Netherlands, England, Wales and Ireland - Past and Prospects; a demographic model	Mr Gert de Graaf, Netherlands
P31	Determining the prevalence of persons living with an intellectual disability in Nova Scotia	Dr Deborah Norris, Canada
P32	A Survey of Experiences of People with Down Syndrome in New Zealand	Dr Susan Foster-Cohen, New Zealand
P33	Epidemiology of Down Syndrome	Ms Stella Forti, Italy

Genetics

P34	Oxidative Stress and Immune Dysfunction in Down Syndrome	Professor Aishah Adam, Malaysia
P35	Relationship of Antioxidant-oxidative stress status and immune function in Down Syndrome	Dr Mizaton Hazizul Hasan, Malaysia
P36	Assessment of the paraoxonase and arylesterase activity PON1 in dependence on 55(L/M) and 192(Q/R) DNA polymorphism in adult patients with Down syndrome	Ms Pavel Sykora, Bratislava

Education

P37	Comparative Study of the Social Activities, Participation and Friendships of Irish Adolescents with Down syndrome, attending Mainstream and Special Schools	Loraine Matthews, Dr. Shay Caffrey, Ireland
P38	Development of tools for assistance to the formulation and the implementation of the life project of persons with Down Syndrome	Marie-Claire Haelewyck & Jean-Paul Champeaux, France
P39	School inclusion of children with Down Syndrome in school of all	Ms Anna Lastella, Rome
P40	Ignoring distractions: A study of Visual Attention in adolescents and Adults with Down Syndrome	Ms Tamara Dawkins, Canada

Education cont'd

P41	Multiple-choice tests with corrections allowed for people with Down syndrome and autism	Dr Elizabeth Monari Martinez, Italy
P42	Investigating the early reading abilities of children with Down syndrome	Ms Anne van Bysterveldt, NZ
P43	Inclusion of Down syndrome persons in the national system of education: reality and desiderata	Ms Ecaterina Gaidarji, Moldova
P44	Effects of regular versus special school placement on students with Down syndrome – review	Mr Gert de Graaf, Netherlands
P45	"MIMOCAS NUMBERS" – Educational software designed to promote the mathematical skills of children with developmental disabilities	Ms Luísa Cotrim, Portugal
P46	Inclusion of students with Down Syndrome in Secondary Education. A Utopia or a real possibility?	Ms Sonja Uhlmann, Spain
P47	All Communication, All the Time: The DSRI Model and the Centrality of Communication Teaching for Students with Down Syndrome	Mr Andy Loebus, Canada
P48	Research study- Speech and language therapy for children with Down's syndrome Phase 1: systematic literature review and consensus statement	Ms Leela Baksi, UK
P49	Developmental Trajectories for Young Children with Down Syndrome	Ms Stephanie Bennett, UK
P50	Wellbeing for children and young people with Down Syndrome in New Zealand: A conceptual framework	Ms Maree Louise Kirk, NZ
P51	Developing Advocacy Skills through Group Work	Dr Siobhan Mac Cobb, Dublin
P52	Inclusive Education Maximising resources	Ms Rosalind Threadgold
P53	Karlstad model	Margareta Hallner & Rigmor Bostrom, Sweden
P54	Phonological Awareness of Children with Down Syndrome: Its Role in Learning to Read and the Effectiveness of Related Interventions	Dr Chris Lemons, USA
P55	Auditory Instruction: A Third Option	Mr Cameron Bonertz, Canada
P56	A New Zealand resource to support successful inclusive transition of children with Down syndrome into daycare and school	Mrs Zandra Vaccarino, NZ

Mental Wellness

P57	Lifestyle of people with Down syndrome in the south region of Brazil	Professor Alexandre Marques, Brazil

Speech and Language

P58	Association between mouth breathing and tongue protrusion in children with Down Syndrome	Dr Rubén López-Pérez, Mexico
P59	Investigating the effectiveness of integrated phonological awareness intervention for children with Down syndrome	Ms Anne van Bysterveldt, NZ
P60	Unique and Intense: A Model for Speech Language Pathology Service Delivery and Teaching of Communication for Students with Down Syndrome	Mr Andy Loebus & Ms Jennifer Sheilds, Canada
P61	Vocabulary development in Italian children with Down syndrome	Ms Laura Zampini, Italy
P62	Karlstad modellen - Johansson Language Methods	Ms Jeanette Persson, Sweden
P63	Study to evaluate the efficacy of The Listening Programme in improving auditory skills and speech for children with Down syndrome	Mrs Gwyneth Jeyes, UK
P64	"Sign Language Workshop": a communication support program to promote early communicative skills in children with developmental disabilities	Ms Luísa Cotrim
P65	Communication At Work	Mr Ally Attwell & Mrs Debbie Rickard, New Zealand
P66	Chatter Challange	Ms Anne Squire, Australia
P67	Building a young child's Language Skills without pain and suffering	Ms Mary Frances Edwards and Ms Diane Lowry
P68	Structuring a Social Communication Group for young Adults with Down syndrome	Ms Diane Lowry & Ms Caitriona Ryan
P69	Toys That Stimulate Language	Ms Diane Lowry & Ms Mary Frances Edwards, Ireland

Quality of Life

P70	Trying to get over prejudice on Down Syndrome	Mr Tomoko Hasegawa, Japan
P71	Discrimination in Immigration - A Case Study in Strategy	Miss Catherine Alpine, Australia
P72	The Healing Powers of Journalling	Ms Erin Lane, Canada
P73	Katie's Excellent Adventure	Ms Katryn Edwards, USA

Life Possibilities

P74	My Life My Choice	Dr Ghasem Norouzi, Iran

Hearing /ENT

P75	Otological Manifestations in People with Down Syndrome	Dr Howard Savage Jones & Ms Theresa Frawley, Ireland
P76	ENT manifestations people with Down Syndrome	Dr Howard Savage Jones & Ms Theresa Frawley, Ireland
P77	Obstructive Sleep Apnoea Syndrome (OSAS) in children with Down syndrome – An Assessment of prevalence and symptom frequency in an outpatient Down Syndrome population	Dr Marian McGowan, UK

Employment

P78	Employment- Pathways via Sport & Recreation	Ms Catherine McAlpine, Australia
P79	Not Just a "Job" Anymore: Career Opportunities for Adults with Down Syndrome	Dr Melissa Rowe, USA
P80	Aspects of the working experience in people with Down syndrome	Dr Eduardo Bilboa, Brazil

Independent Living

P81	The Israeli Down syndrome youth/graduates movement	Rivkah Sneh, Israel

Physical Activity

P82	A Pilot Study to Investigate the Level of Physical Activity in Adults with Down Syndrome	Dr Nora Shields, Australia

"If you have an apple and I have an apple and we exchange apples then you and I still have one apple. But if you have an idea and I have an idea and we exchange these ideas then each of us will have two ideas"

George Bernard Shaw

"When I went to those great cities
I saw wonders I had never seen In Ireland,
But when I came back to Ireland
I found the wonders there waiting for me"

George Bernard Shaw

Day One

Thursday 20 August 2009

Plenary Lectures

Rooms of presentation are coded:
MH (MAHONY HALL)
TH (THEATRE)
BS AND CODE (BUSINESS SCHOOL)
NS AND CODE (NURSING SCHOOL)

Life Possibilities

May Gannon, BSc Counselling and Psychotherapy, MA Dramatherapy, IRELAND

PL1 MH

When my son was born in 1980 I saw few possibilities in life for him. In fact according to parents and professionals who advised me, there was only one possibility for his life path. He should attend a special pre-school, a special school and then participate in a workshop until his death, probably at an early age. In fact there was an agency near me which would provide me with a service from the "cradle to the grave". When I questioned this path I was looked at with pity as a mother who had not accepted her son's disability yet.

After twenty five years of working in a voluntary and professional capacity I can now say that for people with Down syndrome nothing is impossible. This presentation will trace the development of a family moving from a state of helplessness to one of taking control of their own destiny as they realised that life by its very nature surprises and challenges us to change our value system and be innovative and accepting of difference. Michael, my son, advises parents to "forget the Down syndrome part of me, just see me, I am a person, a human being and I can do most things in life. I am full of the joys of life". In 1980 I did not believe that such a statement from a person with Down syndrome was possible. There are parents starting on the road today who are only learning that life has endless possibilities for their son or daughter.

Self Concept

David Hingsburger M.Ed, CANADA

PL2 MH

No matter how much the word 'diversity' is tossed around, the world does not look kindly on difference. It takes more of this thing we call self esteem to manage to live well in a world that doesn't want you to live at all.

Caring Doctors

Prof Conor Ward PhD MD, FRCP, Langdon Down Centre Trust, IRELAND/UK

PL3 MH

The moving force behind the development of special services was not a doctor of medicine but a doctor of Divinity, the Rev Andrew Reed. Preaching in the country he had seen "wretched idiots" harassed and reviled. He sent Mrs Plumb, a member of his congregation to count the destitute " idiots" in Hackney in London. She found 28 boys on street corners. The Rev Reed set out to visit centres abroad and convened an influential London committee to advance the project of providing facilities for education and training. Dr John Connolly, the reformer of the psychiatric services, and Dr James Little who described cerebral diplegia helped him from the beginning. Twin institutions were opened at Park House in Highgate and out of Essex Hall at Colchester. Contemporary lithographs show the spectrum of activities provided. Doctor Martin Duncan served Cold gesture from 1852 to 1871. He was also a noted geologist and a fellow or of the Royal Society. He found time to write a Manual for the Classification, Training and Education of the Feebleminded and Idiotic The Earlswood Asylum for Idiots, the third of Andrew Reed's foundations opened in 1858. Poor medical administration attracted adverse publicity. Doctor John Langdon Down, a rising star in the medical firmament, was appointed to reform the system. Ball for a period of 10 years Earlswood developed an international reputation and Langdon down made many contributions to medical knowledge, apart from specifically identifying what came to be known as Down's syndrome. The tradition was continued in Normansfield, the centre which he subsequently set up to cater for dependence of upper-class families Normansfield was destined to became the headquarters of the Down's Syndrome Association.

Genetics

Professor David Patterson, Senior Scientist of the Eleanor Roosevelt Institute, USA

PL4 MH

Down syndrome is the most common genetic cause of significant intellectual disability in the human population, occurring in roughly 1 in 700 live births. It is also accompanied by developmental differences in many other bodily systems, including predisposition to Alzheimer's disease and leukemia, but a significant decrease in the incidence of certain other forms of cancer. Down syndrome is caused by trisomy of all or part of the set of genes located on chromosome 21. However, the genetic mechanisms leading to the phenotype of DS are not yet known. Although the complete DNA sequence of most of chromosome 21 is known, we still do not know the functions of all the protein producing genes on chromosome 21. In addition, recent advances in genetics indicate that regions of chromosome 21 that do not lead to production of proteins may be important for Down syndrome. Recent findings about the structure of the human genome and of chromosome 21, in particular, and studies on mechanisms of gene regulation will be discussed. These include variations in the number of copies of particular regions of chromosome 21, natural variability of gene activity levels, mechanisms of control of gene activity, and the complex relationships between gene activity and protein function and development and metabolism. Current knowledge about these genetic complexities and their likely importance in the context of DS will be discussed. In particular, the relationships between gene activity and phenotype will be discussed. The use of mouse models to study Down syndrome will be discussed and examples of these studies will be considered.

Lessons Learned and Family Needs

Professor Juan Perera, PhD., Palma, SPAIN
& Introduction by Alex Snedden, Self Advocate, NEW ZEALAND

PL5 MH

The family constitutes the nucleus that in the most constant, involved, selfless and closest way and for the longest time is by the side of the person with Down Syndrome. If the family functions properly, the person with Down Syndrome makes progress. It is evident that this fundamental nucleus has needs, and that these needs have changed over the last ten years.

In this plenary session I am going to summarise the most pressing needs of families with a member with Down Syndrome. I will base this firstly on the analysis of six of the most interesting and comprehensive studies that have been carried out in developed countries in recent years, without overlooking developing countries in Africa, Asia and Latin America, from which we hardly have data and the few details we do have are pitiful and limited to survival, demanding human rights and basic healthcare and education. And secondly, on my own personal experience of nearly 40 years working and supporting families.

What are these needs?: 1) Specific support for training in Down Syndrome and caring for the health, education and upbringing of the child with Down Syndrome. 2) Financial aid to help tackle all the expenses arising from caring for a person with Down Syndrome. 3) Feeling accepted, listened to and not judged. 4) Psychological support at the time of diagnosis and during different phases of the life cycle. 5) Help in the home directed at all members of the family and especially at mothers. 6) Having more time to themselves: respite and leisure services, etc. 7) Having clear ideas on education for the life of their child with Down Syndrome and participating in the decisions that are taken regarding it from the services. 8) Being able to reconcile their family life with their work. 9) Active integration into specific Associations for Down Syndrome. 10) Access to technically trained professionals prepared to focus on different phases of the life of the person with Down Syndrome. 11) Having a clear answer to the question 'what will become of our child when we can no longer be there for him/her'. 12) Release from stress and reinforcement of the emotional balance of parents and siblings. 13) Being able to use new technologies as a source of information.

I hope that the presentation of these needs of families will spark many questions which we will try to discuss and answer in the corresponding "meet the experts" session.

Early Intervention in Down syndrome

Dr Sheila Macken M.B., B.Ch., FRCP(C), FRCPI, IRELAND

PL6 MH

Early Intervention involves supporting and promoting complex developmental processes in children affected by Down syndrome as they take their place in their family and wider community. Dr. Macken will review general principles underlying early intervention with children and their families from the time of diagnosis through to school entry. She will provide an overview of best practice, with reference to research and evidence supporting different approaches to the child with Down Syndrome.

Managing Life with Down Syndrome

Ms Cora Halder, Director of the German Down-Syndrome Infocenter, GERMANY

PL7 MH

Some people with Down syndrome master their life better than others. Even then when the environment they grow up in, their state of health and their developmental starting position are similar. What is the reason for this better coping-ability?

What kinds of resources are necessary to obtain a good life quality, to manage life with all the everyday stressors and to be able to lead a fulfilled and happy life?

Are people with Down syndrome able to build up such resources?

How can families strengthen their children and youngsters with Down-syndrome to better cope with stressors they encounter in daily life?

A helpful concept in this process can be the salutogenesis philosophy, developed by Aaron Antonovsky (1923-1994). The salutogenesis concept concentrates on the relationship between well-being, health, stress and coping. In my talk I will focus on the main aspects of the salutogenesis and show their importance for the life of individuals with Down syndrome.

Meet the Expert

Genetics

Professor David Patterson

ME1 MH

Early Intervention session

Dr Sheila Macken

ME2 NS HG20

A panel of clinicians experienced in the provision of Early Intervention will be available for discussion. Questions may be submitted beforehand in the box at the registration desk. Individual cases cannot be discussed, but issues related to different aspects of early intervention will be discussed.

Lessons Learned & Family Needs & Managing Life & Down syndrome

Professor J Perera & Ms Cora Halder

ME3 BS QG13

Professor Perera and Ms Cora Halder will undertake a combined Meet the Expert session and will explore the lessons learned and family needs and ways to manage life well and Down syndrome.

Life Possibilities

Ms May Gannon & Team

ME4 BS QG15

This presentation will expand on the development of a family moving from a state of helplessness to one of taking control of their own destiny as they realised that life by its very nature surprises and challenges us to change our value system and be innovative and accepting of difference.

Self Concept

Mr David Hingsburger, Canada

ME5 TH

No matter how much the word 'diversity' is tossed around, the world does not look kindly on difference. It takes more of this thing we call self esteem to manage to live well in a world that doesn't want you to live at all.

Oral Presentations

The Role Of Parents In Early Intervention

Gerald Mahoney & Frida Perales, Case Western Reserve University, USA

01 MH

The presentation will describe research and intervention studies related to the critical role that parents play in attaining positive early intervention outcomes with children with Down syndrome and other disabilities. Videotaped examples will also be used to illustrate the style of parent-child interaction that is most effective at enhancing the development

To describe published empirical research findings related to the following issues:

(1) how parent interaction contributes to the cognitive and communication development of young children with DS;

(2) how parents' interactions during the early childhood years relates to later academic and developmental attainments; (3) how parents influence early intervention outcomes even when interventions that do not involve parents; and (4) how intervention programs that promote responsive parent-child interaction have positive influences on children's development

This presentation will review and illustrate findings from several studies.

This research has produced the following findings:

(1) Efforts to involve parents in early intervention as children's teachers have not been effective at promoting children's development;

(2) Parental Responsiveness is one of the most important influences on the development of young children;

(3) Parental Responsiveness plays a critical role in the effectiveness of early intervention services that do not include parents;

(4) Interventions that focus on enhancing parental responsiveness are highly effective at enhancing early developmental functioning of children with Down syndrome and other disabilities;

(5) Parental responsiveness with young children has long term developmental benefits;

Efforts to implement early intervention must design service systems such that parent-child interaction can be a major focus.

Leading The Way In Galway Ireland - Early Engagement & Communication

Mari Caulfield, A Community Nurse And Parent, Down Syndrome Galway Branch, Mari Caulfield, Independent Speech And Language Therapist And Community Nurse Dept. Brothers Of Charity, IRELAND

02 MH

This group is in its ninth year of running in Galway and was initiated by a small group of parents who were attending early intervention services with the Brothers of Charity. They had visited the centre of excellence at Portsmouth: The Sarah Duffen Centre, and dreamt of replicating the service they saw there.

In response to their request, the Community nurses joined forces with Mari Caulfield speech and Language therapist in a very successful joint venture between the Down Syndrome Galway Branch and the Brothers of Charity. Services are provided by 5 community nurses and the venue from the Brothers of charity.

With scarce speech and language therapy resources this was an innovative way to respond. The children enter this project known as the Little Owls, at 12 mths and remain attending the service until they are placed in Preschool. The toddlers attend with a parent, in a group of six to seven others and proceed through an intense series of activities for the duration of an hour and attend fortnightly each term. Families attend Lamh trainng sessions, networking and support is an ongoing natural outcome and many life long friendships are born between the children and parents. A re-union after the first five years proved a very touching and successful day!

The success is seen in the joint integrated approach between a speech and language therapist and community nurse service. Community nurse support remains an ongoing service between groups and carryover is then much easier and successful. The early intervention domiciliary service serves to complement the fortnightly groups.

It has become an expected and established part of the service for the population of babies and children with Down Syndrome. All of the staff remain the same for the past 9 years which lends a continuity and deepening of expertise and experience.

The Effect Of Educational And Psychological Family-Centered Early Intervention On The Developmental Performance Of Children With Down Syndrome

Salar Faramarzi Of University Of Isfahan, Mojtaba Amirimajd Of Abhar Islamic Azad University, University Of Isfahan, IRAN

03 MH

The term psychological and educational family-centered early intervention refers to both a philosophy of care and a set of practices.

The purpose of this study was to examine the effect of psychological and educational family-centered early interventions on the Developmental Performance of Children with Down syndrome.

So an experimental and a pretest-posttest control group design method were applied. Parents of 36 children with Down syndrome were chosen as sample size of the study. Vineland Adaptive Behavior Scale, was used to evaluate the Adaptive Behavior And Winders motor developmental checklist and Gesell psycho-motor scale was used to motor skills, and a language development scale which is a researcher made scale with calculated validity and reliability, have been applied to measure the language development. gathering and analysis of the data with statistical analysis of covariance.

After gathering and analysis of the data, the following results were revealed: The significantly difference between the performance of children with Down syndrome, in both control group and the experimental group in Adaptive Behavior, motor and language development scales.

It shows that psychological and educational family-centered early interventions have an effect on Adaptive Behavior, motor and language development of children with Down syndrome.

Early Intervention Services

Parvathy Viswanath, Aikya - Centre To Integrate The Different, INDIA

04 MH

Early intervention services have a significant impact on the parents and siblings of an infant or young child with Downs Syndrome. The compounded stress of the presence of a child with disabilities affects the family functioning and interferes with the child's development. Early intervention results in parents having improved attitudes about themselves and their child, improved information and skills for teaching their child, and more release time for leisure and employment

There are three primary reasons for intervening early :

1. to enhance the child's development
2. to provide support and assistance to the family, and to maximize the child's and family's benefit to society.
3. A third reason for intervening early is that society will reap maximum benefits.

Early intervention applies to infants and children of 0-6 years. EI programmes may be center-based, home-based, hospital-based, or a combination.

EI Services include special instruction, speech-language therapy, occupational

There is evidence – both quantitative both quantitative and qualitative – that early intervention increases the developmental and educational gains for the child, improves the functioning of the family, and reaps long-term benefits for society.

Early intervention has been shown to result in the child: (a) needing fewer special education and other habilitative services later in life; (b) being retained in grade less often; and (c) in some cases being indistinguishable from nonhandicapped classmates years after intervention.

Early Intervention Maximises individual potential of Children with DS.

Learning To Move

Raquel Barateiro, Miguel Palha, Portuguese Down Syndrome Association, PORTUGAL

05 MH

Learning to Move is an audio-visual teaching tool where organised sets of activities and strategies were purposefully designed to develop the fine and gross motor skills of children with Special Education Needs (especially children with Down syndrome).

PROJECT GOALS:

- promote the psycho-motor development
- define specific objectives in the areas of fine and gross motor skills within a multidisciplinary team.
- encourage family-child intervention
- meet family needs in motor intervention
- propose a range of tasks and materials according to the child's psycho-motor profile
- allow therapists fast searches by different categories: intervention areas, age, goals and skills.
- promote early motor skills in children of school-going age
- lessen damaging effects of motor impairments.
- create a versatile system that allows the introduction of new activities/ strategies.

This multimedia Guide fully integrates and supports the Individual Education Programme for children with special needs and can be used to work towards the objectives set thereof.

One remarkable feature of this 'Project' is its unique audio-visual tutoring, leading parents/teachers through strategies devised purposefully to get the child to reach specific objectives

We felt that there was a pressing need for a dynamic, practical, audio-visual teaching tool to serve as support for parents, teachers, and all who deal with children between 0 and 7 years old, with or without motor disorders, children with mental retardation and new-borns at risk due to premature birth.

We intend to introduce this Guide to all the Special Education Teams, and families so as to enable them to continue their work using this new tool.

Re Writing The Data On Down Syndrome

Karen Gaffney, Karen Gaffney Foundation, USA

06 TH

The audience will hear from a young woman with Down syndrome who benefited from early intervention and full inclusion all through her academic career. Karen Gaffney, the presenter, was able to earn a regular high school diploma and complete a 2 year college degree. Karen is a regular keynote presenter, inspirational speaker at conferences in the US.

She is an accomplished long distance swimmer, including a nine mile solo swim across Lake Tahoe and a relay swim across the English Channel.

She will share her experiences and talk about her efforts to improve inclusion in the schools and communities for people with Down Syndrome. More information on karen and her work can be found at www.karengaffneyfoundation.com

As Karen presents, Family members and Professional attendees will see first hand the impact of inclusive education as well as inclusion in the community and the work place.

Karen will tell her story as well as the story of others her age who, because of early intervention and inclusion in schools, are living, working and contributing in their communities (136)

Karen Gaffney will deliver a stand up presentation with powerpoint slides and short video if time permits.

Karen's presentation will reinforce the importance and impact of early intervention and inclusive education, and will inspire families and professionals on the positive outcomes of both.

Inclusive Education At The Post-Secondary Level In Western Canada – A Review

Michael Shaw, University Of Manitoba, University Of Manitoba, CANADA

07 TH

In Canada inclusive education is firmly established in the majority of primary and secondary schools. The concept that inclusive education should be extended to all individuals, including young adults, is relatively new. We examined the amount and structure of such programs in western Canadian universities and attempted to develop a "best practice model".

To determine the structure, including both entrance mechanisms and funding models, of inclusive education at western Canadian universities. As a result of the information collected a best practice model can be developed and provided to all institutions in the hope of greater penetration of inclusive education in Canadian universities.

All 28 Universities in Western Canada with membership in the Association of Universities and Colleges of Canada were contacted to determine the presence of an inclusive education program for members of the community who would otherwise be denied traditional entrance due to cognitive disability. This information was used for a more detailed examination of a sub set of the 28 Universities.

Much more needs to be done, particularly among Universities that are publicly funded, if Canada is to be compliant with the UN Convention on the Rights of Persons with Disabilities. There is no widely adopted system that is common across more than 2 institutions. The recognition that all learners are life-long learners is essential to a truly inclusive educational system.

Inclusive Post-Secondary Education: A Promising Path To An Inclusive Life

Uditsky, B, M.Ed, Ceo, Alberta Association For Community Living and Hughson, E.A., Ph.D., Director, Community Rehabilitation & Disability Studies, Faculty Of Medicine, University Of Calgary, Alberta Association For Community Living, CANADA

O8 TH

Inclusive post-secondary education has proven to be an effective means of enabling individuals with Down syndrome to pursue their dreams of a meaningful life in community. The authors have been including individuals with Down syndrome in universities and colleges for more than 20 years. .

This presentation will illustrate the remarkable success stories from learning and belonging to finding meaningful employment. The experiences of parents, peers and faculty will be shared. Information will be provided on how to create and ensure quality inclusive post-secondary opportunities.

A DVD that powerfully highlights the experiences of students including parents, peers and faculty will be shown along with Powerpoints. Each participant will receive a copy of the DVD plus a booklet on inclusive post-secondary education written by the presenters and a copy of the materials used for determining quality inclusion within tertiary institutions.

Research conducted by the authors and others will be shared on outcomes of inclusive post-secondary education. Information will be provided on the courses and programs of study in which students are included, their experiences in their own words and those of their peers, parents and instructors. Approximately 80% of students secure employment typically utilizing natural supports.

While this presentation focuses on the successful experiences and outcomes of adults with Down syndrome who are fully included in post-secondary institutions it is particularly impactful for parents of very young children as it reminds them of the necessity to hold onto their dreams, sustain high expectations and pursue the promise of an inclusive life.

Nourishing The Spirit Of People With Down Syndrome

Dr Ian Dickson, Institute Of Theology, Queens University Belfast, European Society For The Study Of Theology And Disability, NORTHERN IRELAND

O9 TH

The history of intellectual disability is largely a record of medical, social and educational perspectives and advances. The person with Down syndrome is a highly scrutinized human. The movement 'into the open' of people with intellectual disability has exposed our difficulties with difference. The journey for society towards inclusion remains a long one. This paper argues that part of this process is the recognition that people with Down syndrome are not only capable of socialization and education but also of spiritual development.

Four considerations are explored:

(1) The indefinableness and commonality of being human. A consideration of 'something beyond' (spirit) within all human beings that demands attention and nourishment.

(2) The contribution of faith-based spiritualities. A consideration of whether there is 'something more open' about a person with Down syndrome and the possibility that such openness and uncomplicatedness aids spiritual development.

(3) The understanding of theology as reflection on spiritual experience. A consideration of what constitutes spiritual experience and whether it necessarily requires a sophisticated cognitive process and high articulation. Does the teaching of Jesus Christ, for example, inform a different perspective, one devoid of elitism and exclusion?

(4) The potentiality for reciprocal nourishment. A consideration of people with Down syndrome as spiritual contributors within faith communities (vehicles for friendship, care and opportunity). How might these communities overcome negative attitudes to disability and token forms of integration and so provide wider society with a model of inclusion?

A holistic understanding of people with Down syndrome is unachievable without these and similar considerations. The spiritual and theological dimensions of being human must be added to the on-going medical, social and educational perspectives and advances

EU PROJECT MOTE

Project Team: Dr. Paola Vulterini (Project Manager), Anna Contardi (AIPD), Carlotta Leonori (AIPD), Gráinne Murphy (DSI), Laura Krauel (Aura), Davis Simo' Pinatella (Ramon Llull University, Spain), Camilla Jydebjerg & Tina Mou Jakobsen (Denmark), Luisa Grech & Elena Tanti Burlo (Malta), Pat Clarke (DSI), May Gannon (DSI)

O10 TH

It is characteristic of a modern democracy that all adult citizens have an equal opportunity to exercise active political influence. Political decisions influence the lives of people with learning disabilities in the same way as they influence the lives of everybody else. Looked upon as a group, people with learning disabilities are often one of the population groups whose life conditions are most dependent on political decisions. Nevertheless, people with learning disabilities are still one of the population groups who are most frequently excluded from democracy.

British and Swedish surveys show that the level of participation in elections by people with learning disabilities is very low compared with the rest of the population . A Danish survey points out that many persons with learning disabilities do not experience a natural expectation of having an opinion of their own or being responsible for themselves during their upbringing or at school

The overriding purpose of the My Opinion, My Vote (MOTE) project is to make people with learning disabilities more aware of their political rights and to create better opportunities for them to use these rights. The project is based on the assumption that there are various barriers preventing people with learning disabilities from exercising their political rights on an equal footing with others. One barrier is lack of awareness and knowledge of political rights among people with learning disabilities, their relatives, and persons in the caring professions. Another barrier is a lack of awareness of the importance of political participation by people with learning disabilities in society as a whole. A third barrier is reduced accessibility of electoral information at the times preceding and during elections.

A qualitative interview survey of three rounds among twenty people with learning disabilities and professionals from each participating country will be carried out during the project period. An awareness campaign is to be implemented. The campaign has completed its first phase and focused on people with learning disabilities, politicians, and public authorities

An education programme comprising of two modules is also in the process of design and testing.

Learn To Read To Support Language Program - Promoting Speech, Language And Literacy

Teresa Condeço Psym, Luísa Cotrim Psym, Miguel Palha Md, Portuguese Down Syndrome Association/Child Developmental Centre Differences, PORTUGAL

O11 BS QG15

According to Prof. Sue Buckley, the speech and language impairments seem to be caused by factors such as auditory loss, impairment in auditory processing skills and

in working memory skills.

On the other hand, if the communicative processes were supported by language visualization, the outcome would be a better performance in linguistic processing and production.

In our presentation, we propose to highlight the main features of the "Learn to Read to Support Language" Program, its methodology and strategies and the software developed to facilitate children performance.

"Learn to Read to Support Language" was designed to enhance speech, language and early reading skills. We also introduce "Mimocas Games", an interactive educational software game, especially designed for use with children with Down syndrome. Its key objective is to teach youngsters with Down's syndrome how to read by means of a visual learning process. We present you some of the strategies we have worked out to promote comprehensive and expressive language like personalized powerpoint books and worksheets based on "Mimocas Games".

This Program is a great help to parents, teachers and therapists when outlining the individual educational program. The computer use is a powerful tool in visual learners and today most of our intervention work makes use of image, movement and sound.

Visual strategies have shown itself as an excellent tool for promoting motivation and consequent attention and concentration in the procedure teaching / learning with children with Down's syndrome.

Teachers Perspectives On The Application Of The Handwriting Without Tears® (HWT) Programme With Children With Down Syndrome Attending Mainstream Schools In An Irish Context

Sandra Patton, BSc. COT & Dr. Siobhan Mac Cobb, Trinity College Dublin, IRELAND

012 BS QG15

This paper will present the findings and outcomes from the teacher's perspectives on a large scale study that was conducted in 3 counties in the Republic of Ireland. The purpose of the study was to investigate the application of the HWT® programme using a collaborative approach which involved 50 children with Down Syndrome, their parents, teachers and an occupational therapist. This study was conducted over a 10 month period in 2006/2007.The children ranged in age from 5"10 years.

This presentation will report on the teacher's perspectives on the application of the HWT® programme.

A mixed methods approach was used. This included pre and post intervention questionnaires with 45 teachers, one pre intervention with 3 teachers and one post intervention focus group with 4 teachers, field notes recorded during the intervention phase and cross case analysis using a case study design.

The results being presented will include teacher's perspectives on:

- Benefits of using the HWT® programme
- Limitations of using the HWT® programme
- Practical issues
- The Collaborative approach

Benefits were the structured approach, variety of materials, simple language of the HWT® programme and increased task engagement by the child.

Limitations were the child following a different scheme to classmates and the emphasis on capitals.

Practical issues included the need for implementation on a one to one basis and school staff collaboration.

The collaborative approach provided the teachers with support and guidance.

Recommendations include teacher training and occupational therapy support in implementing the HWT® programme.

Exploring The Effectiveness Of Phonics-Based Instruction For Children With Down Syndrome

Chris Lemons, Ph.D., University Of Pittsburgh, School Of Education, University Of Pittsburgh, USA

013 BS QG15

Practitioners are increasingly expected to provide reading instruction to students with cognitive disabilities to help them become literate. Whereas a phonics-based approach to reading instruction is regarded as a 'best practice' for most young children, its effectiveness for children with cognitive disabilities is unclear.

The purpose of this study was to explore this issue for a sample of 24 children with Down syndrome (DS) between the ages of 7 and 16 years. More specifically, the study's purpose was to explore the effectiveness of phonics-based instruction for children with DS and to model individual children's reading growth to identify specific child characteristics predictive of this growth.

24 children with DS received 30 hours of one-on-one phonics-based reading instruction. Growth on various early reading skills (i.e., letter sounds, decodable word reading, nonsense word reading, sight word reading) was modeled using Hierarchical Linear Modeling (HLM).

Results indicate that a majority of children demonstrated statistically significant growth in letter sounds, and reading of taught sight words and decodable words. Children with DS who entered the study with more advanced word identification skills made greater gains in decodable word reading; those with more advanced phoneme segmentation skills made greater gains in nonsense word reading.

Overall, findings support the idea that children with DS can benefit from an intensive, phonics-based reading intervention. Apparently, at least for a portion of these children, 'evidence-based' practice may prove effective and practitioners should not shy away from providing this type of reading instruction to a child solely because she or he is a child with DS. It is also clear, however, that not all children with DS will benefit from this instruction, at least initially.

Teaching Reading To Individuals With Down Syndrome

Denise MacDonald, Ereadingpro, CANADA

014 BS QG15

Under the direction of Founder Denise MacDonald (formerly co-founder of the Out of the Box Reading program), attendees learn the basic building blocks of teaching children to read using the whole word approach.

Numerous studies have shown that a large percentage of children are visual learners, particularly children born with Down syndrome. Visual learners favor the use of their right-brain when reading, and tend to read words as pictures. As such, these children need to see the whole word first, and make a mental picture of what the word looks like, prior to understanding the phonetic components of the word.

This workshop offers parents and educators the TOOLS that have been missing, fully supporting the existing research of how children with Down syndrome (visual learners) learn to read.

By following a detailed progression from single words to couplets, phrases, and sentences (using books), participants are shown how to create a list of vocabulary, and how to complete the progression from the single words through to sentences using this vocabulary.

Participants can expect to learn:

- About learning styles and learning strategies;
- Reasons why children struggle with reading;
- How to set up a reading program;
- How to create flashcards and books;
- How to present and use flashcards effectively.
- Importance of consistency and a presentation schedule;
- How teaching reading improves speech, language and memory development;

eReadingPro has created an amazing and simple method for teaching reading to individuals with Down syndrome and would like to share it at your conference!

Creating Literacy: Young Children With Down Syndrome And Typically Developing Children Constructing Meaning Together In Inclusive Classrooms

Dr Christopher Kliewer, Department Of Special Education, University Of Northern Iowa, USA

O15 BS QG15

I will explore how literacy and communication are fostered in inclusive early childhood classrooms for children with Down syndrome and their typically-developing peers in the inclusive preschool and kindergarten classroom where literate and communicative participation is fully supported.

Making use of extensive video taken in our participating classrooms as well as a mass of collected materials, participants will critically examine young children's developing capacity with signs and symbols, beginning with visual-tactile signs used in play, then moving to pictorial signs, then moving to orthographic signs (or the lettered signs of printed language). A description of how children with Down syndrome have historically been denied access to literacy opportunities will lead into a detailed description of how children so-labeled are being supported as full citizens of the inclusive early childhood literate community. This support occurs through 4 identified Currents of Literacy. These currents include:

1) Making sense of the stories of others. The role of Assistive Technology and Augmentative & Alternative Communication will be described.

2) Finding and expressing meaning in one's own experience through narratives crafted from visual, orthographic, or tactile sign systems i.e., Important to literacy development is the need for a child to understand that her or his own experiences, ideas, and emotions are worthy of expression and can be conveyed through visual, orthographic, or tactile sign systems. Children with Down syndrome must be understood as full and valued citizens of the classroom with rich experiences, ideas, and stories to share. The role of Assistive Technology and Augmentative & Alternative Communication will be described.

3) Developing complexity with visual, orthographic, or tactile sign systems in sustaining or generating narratives.

4) Deriving Joy and Other Affective Forces from Engagement with Visual, Orthographic, and Tactile Sign Systems are recognized and valued. The role of Assistive Technology and Augmentative & Alternative Communication will be described.

Video documentation and materials will provide detailed descriptions of children's literate growth as practiced in classrooms that promote the four currents of literacy.

Introducing An Intervention To Improve Reading And Language Outcomes For Children With Down Syndrome In Mainstream Classrooms

Kelly Burgoyne (Down Syndrome Education International), Sue Buckley (Down Syndrome Education International), Charles Hulme (The University Of York), Margaret Snowling (The University Of York), Down Syndrome Education International, UK

O16 BS QG15

Introducing an intervention to improve reading and language outcomes for children with Down syndrome in mainstream classrooms

Down Syndrome Education International and the University of York have recently been awarded National Lottery funding to support research which aims to improve reading and language outcomes for children with Down syndrome. This paper outlines plans for a 2-year reading and language intervention developed for children with Down syndrome in mainstream education.

Evidence suggests that an integrated approach to teaching reading and language skills may be particularly effective for children with Down syndrome. This project will develop and evaluate a programme which utilises a combination of phonics and oral language skills training to improve reading and language outcomes for children with Down syndrome.

This is a randomised control study in which teaching assistants will be trained to deliver the intervention to 52 children aged 6-9 years in the York and Portsmouth areas. Twenty-six children will act as a control group for the first intervention phase and receive the intervention in the second phase. Children will be assessed on a variety of measures and progress monitored to evaluate the impact of the intervention.

The first intervention phase will commence in September 2009. Results from the initial assessments of language, reading and cognitive skills will be presented and discussed.

It is anticipated that the intervention will result in significant improvements in the reading, speech and language skills of children with Down syndrome, and will be effectively integrated into schools' teaching practice.

Families & Professionals: What Really Matters II

X.López-Oliver, Asiquipu, SPAIN

O17 BS QG13

This paper raises questions about what are the priorities for parents and professionals and which areas of conflict can be observed when the goals are similar but not identical. A questionnaire was given to a group of parents asking about what parents want or demand from any therapist, and how they feel about this relationship.

The hope of this discussion is to challenge the audience and to revise the 'messages' of early intervention and the attitudes that drive the disability system in general. It is not claimed to state any 'truths' to be speak for all parents, or to have any clear cut answers but simply offer some views and experiences with the hope that the questions we raise may move us all a little closer towards doing things better.

Going forward, as any parent, we support all our children through the phases of their lives with the inevitable goal that they will one day leave the family and live independently. Nevertheless we should think seriously about how to achieve it and if other goals may be more important than this one. Some D.S. Adults will talk in the videos about experiences in that areas.

In this second phase of the study, we want to include some new ideas coming from Iberoamerican D.S. Meeting (Argentina 2007)and our own personal involvement in

sport experiences not included in our previous presentations (9th World Congress, Porstmouth D.S. Conference). All that has driven us to a broader knowledge of what we think "really matters" for our children.

Finally, parental education should be addressed. The importance of learning from the professionals is capital for us. One way is attending conferences such as this one for a clearer picture of the problems we are facing at the future, the other is working together in a levelled environment.

Improvising Disability With Music

Dr Sindoor Desai, USA

018 BS QG13

Researchers over the centuries show that human nervous system is like a symphony orchestra with different rhythms, melodies that keep human brain synchronized. When part of the brain is damaged or defective like one in individual born with Down syndrome the natural rhythm of the brain and body is disturbed or not stimulated at all. At this time if an external stimulus is applied to brain the neurological rhythm can be restored to bring back the body in tune. These external stimuli can be in any form like music; body movements (dance) drama, relaxation, art, messages and much more. The healthcare professionals call this an alternative therapy, which they have started to believe has successful outcome when traditional therapies fail.

The following research is discussed and how each works with individuals with compromised intellectual functions :-

Multiple Intelligences: Howard Gardner, Dr. Roger Sperry: Left and Right brain theories.

Dr. Paul MacLean: The Triune Brain, Dr. Elaine de Beauport & Triune Brain

Dr. Suzuki's music: environmental interventions, Carl Orff School work system, Musical Brain: Don G. Campbell, Mozart Effect, Aceregberg Lewis research, Medical and Educational Application of Music by Dr. Raymond Bahr , Gordon Shaw Physicist, Irvin studies, Laurel Elizabeth & Toning. Guided Imagery & Music (GIM), Dr.Tomatitis & Sonic Rebirth Thomas Regelski & Mental Shift , Limbic System.

OUR MESSAGE & MISSION

In Down syndrome: as seen in "Sujeet" genetic over expression damages neurons (brain cells) leading to learning disability but the normal Corpus Callosum (Fibers that connect both sides of brain) still help mental shift and improvisation. Same principle can be applied to "IMPROVISE ANY DISABILITY WITH MUSIC" as well with different approaches mentioned in this workshop.

For the educators and medical professionals that is our message and that is our mission to accomplish through this workshop. We hope you find this information helpful to share with others who could benefit from it.

Iron Deficiency And Down Syndrome

Lynn Rastelli RN BSCN, Lyne Tremblay RN, Mary Pothos MD, Asha Nair MD, Children's Hospital Of Eastern Ontario, CANADA

019 BS QG13

Iron deficiency with or without anemia can impair cognition and affect mood and concentration in children. Down syndrome already presents developmental challenges for the child and their family therefore it is crucial to diagnose and treat iron deficiency as soon as possible.

To define the incidence of iron deficiency in a cohort of children with Down syndrome less than 18 years of age followed at a regional Down syndrome clinic in Ontario, Canada.

A retrospective review of patients' screening blood work taken from July 2005 to July 2008 at the Children's Hospital of Eastern Ontario was undertaken. These lab results were taken from patients who attended their routine Down syndrome clinic visits.

234 (139 males (59.4%), 95 females (40.5%) results were available for CBC and ferritin. Of these, 3 patients or (1.3%; 2 males, 1 female) had evidence of anemia (hemoglobin ranging from75-93 G/L). 60 patients of the 234 (25.6%; 53 males, 7 females) had low ferritin (5 to 23 micrograms/L) with no anemia. 170 had normal ferritin levels and 1 had a higher than normal level of ferritin. Only 1 (male) had associated Celiac disease as the possible cause of low ferritin.

26.9 % of the children undergoing routine blood screening demonstrated iron deficiency. We recommend that full blood count and serum ferritin be measured as part of the routine blood work starting in infancy in the Down syndrome population. Early detection and treatment of iron deficiency can help prevent further compromise of cognitive development.

Survey On Risk Factors For Latex Allergy In Children And Adults With Down Syndrome

Maureen Gavin, Paul Patti and Nancy Andiloro, New York State Institute For Basic Research In Developmental Disabilities, USA

020 BS QG13

Latex allergy can pose a serious health threat children and adults with Down Syndrome (DS). It is a progressive allergy; each exposure to latex increases the sensitization and the risk for developing an anaphylactic reaction. The risk factors that increase the potential for developing a latex allergy are a history of allergies, food allergies, multiple surgical procedures, exposure latex products, and allergic reactions to certain fruits.

A survey was developed to assess risk factors for developing a latex allergy in children and adults with DS.

The survey was distributed to parents and caregivers of children and adults with DS in the United States, Canada and the United Kingdom.

325 parents and caregivers of children and adults with DS responded to the survey. The survey findings indicated that children and adults with DS have multiple risk factors for developing latex allergy. In our survey sample, 64% had one or more surgical procedures, 20% had allergy to one or more medications, 22% had one or more food sensitivities, intolerances or allergies,16% had hay fever, 7% had allergies to band aids and/or surgical tape and 8% had other allergies.

Early recognition of the symptoms and preventative measures are the key to stopping the progression of the latex allergy. Early childhood surgery, multiple surgical procedures, allergic reactions and sensitivities are the risk factors for developing a latex allergy. It is imperative raise the awareness of the risk factors for latex allergy in children and adults with DS.

The Happy Strap

Janet Wichmann, Happy Strap (Pty) Ltd, SOUTH AFRICA

021 BS QG13

I am the mother of Jens who is now 4 years old and has Down syndrome. When he was younger his low muscle tone facilitated manoeuvres that therapists told me should be prevented. With input from family, friends and medical professionals the Happy Strap was designed, developed and patented.

Basically the Happy Strap is designed to keep the legs in the correct position. This helps to groove a neural pathway " especially when worn 24/7.

The Happy Strap prevents abduction of the hips & promotes balance, stability and confidence.

The Happy Strap is comfortable, durable, adjustable & machine washable.

A demonstration of how to put on/take off the Happy Strap & its function will be presented; including a short DVD of the history of the Happy Strap & a case study of Jens.

The aim of the Happy Strap is to increase mobility through stability from as young an age as possible.

Having had first hand experience of the difference the Happy Strap makes, it is my personal aim to pass on the benefits to as many children internationally as possible.

The Happy Strap has proved to be hugely beneficial to many children with low tone on four continents so far. It has been widely accepted & recommended by medical practitioners and parents alike. Many positive testimonials have been received & can be viewed at www.happystrap.co.za .

The Happy Strap is now a proven product and will undoubtedly prove beneficial in cases diagnosed by medical practitioners as appropriate.

Adult Siblings: Early Contributors To Relationships

Monica Cuskelly, The University Of Queensland, The University Of Queensland, AUSTRALIA

022 BS QG27

There is increasing recognition of the importance of adult sibling relationships within families who have a member with a disability. In part, this recognition reflects the understanding that siblings are likely to play a central role in the lives of individuals with a disability as they age. There has been little investigation of adult sibling relationships between individuals with a disability and their brothers/sisters and very few studies have used a longitudinal design to track the development of these relationships.

The aims of this study were to: (1) describe the nature of the sibling relationship between adults with Down syndrome and their adult brothers/sisters; and (2) to investigate the influence of possible childhood predictors of the adult relationship.

Seventy siblings (and their parents) were interviewed about the relationship between the individual with Down syndrome and their brother/sister when both the individual with Down syndrome and the sibling were children and/or adolescent. Siblings were traced through their family of origin and were invited to participate in a postal survey of their current involvement and relationship with their brother/sister with Down syndrome.

Fifty percent of siblings were able to be traced and agreed to participate in the study. Relationships as reported by the sibling were generally positive with regular contact between siblings and their brothers/sisters with Down syndrome.

The perspectives of the individuals with Down syndrome about the sibling relationship would strengthen future investigations of this area of family functioning.

Informing Children Of Their Sibling's Diagnosis Of Down Syndrome

Van Riper, M. University Of North Carolina At Chapel Hill, University Of North Carolina At Chapel Hill, UNITED STATES

023 BS QG27

The process used to inform children about their sibling's diagnosis may play a critical role in how children adapt to the challenges associated with living in a family that includes a child with Down syndrome. Unfortunately, our understanding of this process is limited.

To describe how parents inform children of their sibling's diagnosis of Down syndrome by exploring what parents and children recall of the disclosure experience.

A cross-sectional mixed-methods study of 86 families of children with Down syndrome was conducted in the United States. Participants (109 parents and 69 children over the age of seven) completed a packet of self-report questionnaires.

In most families the informing process was a gradual process influenced by the child's age and developmental level. If the child was younger than the sibling with Down syndrome, the process usually started when the child was between 2 to 5 years of age. Some parents found it difficult to start the informing process. Others said it was rather easy because they started when their children started asking questions. Most parents reported using a combination of informing strategies. While most of the children reported being told, over 12% of the children did not. More than 90% of the children indicated that they would like to learn more about Down syndrome.

Most parents indicated that it would have been helpful to have a guideline or list of suggestions regarding how to inform children of different ages. A list of suggestions will be presented.

Siblings Of Children With Down's Syndrome

Professor Dr. Etta Wilken, GERMANY

024 BS QG27

We sent 207 questionnaires to families, in which a child with Down's syndrome grew up. 116 were answered by sisters and 91 by brothers. The siblings were in the age from 12 to 49 years. The brother or sister with Down's syndrome was in the age range 6 to 46 years.

We got a lot of interesting results:

- There is a difference between having a sibling with Down's syndrome or with another handicap
- Sisters often had more problems during puberty than brothers
- It is difficult to discuss a problem and to solve a quarrel verbally
- The parents (mainly the mother) had often too little time for them

But there were a lot of positive comments also:

- Our family developed special strength in coping with difficulties
- We learnt responsibility and social engagement
- We learnt what is really important in life

Sisters and brothers gave some special advice, which may help parents and other siblings.

The Mexican School of Down Art

Sylvia G. Escamilla, The John Langdon Down Foundation, MEXICO

025 BS QG27

Symbolic expression has allowed our young people to turn their language deficits into shapes and colors, strokes and ink that speak of happiness and pain, of desires and frustrations, of love and misunderstanding, of their late desires and hopes...fine art poems that seek to affirm life from their viewpoint.

Art is, undoubtedly, a means through which they reassert their identity and boost self-esteem.

Use art to develop communication in youths with Down Syndrome.

Encourage the development of abstract thought through artistic work. Promote the full participation of people with Down Syndrome into society.

Teach various artistic techniques

Teach classic and contemporary art history and enrich our student's understanding of fine arts through visits to museums.

Collect the personal life histories of our artists, to establish the relationship between artistic expressions and life's experiences.

Abstract thought, creativity and imagination are stimulated through the arts.

Students can create their own artistic language through which they recognize and manage figure sequence, background, textures, colors and perspective.

Students increase their self-esteem and improve their independence and decision-making capacity, thus promoting their social integration.

We undertook the adventure of promoting an education based on the development of understanding, expression and the creation of symbols. These efforts have been producing valuable results that encourage us to continue in the same direction.

We have the deep conviction that art is a powerful gateway to increase the social integration of our students.

Highlights Of Mexican Down Art

The John Langdon Down Foundation, MEXICO

026 BS QG27

Symbolic expression through the medium of art will be protrayed in highlighting what the young people have developed into shapes and colors, strokes and ink that speak of happiness and pain, of desires and frustrations, of love and misunderstanding, of their late desires and hopes...fine art poems that seek to affirm life from their viewpoint.

Art is, undoubtedly, a means through which they reassert their identity and boost self-esteem.

Identifying Facilitators And Barriers To Physical Activity For Adults With Down Syndrome

Nora Shields, Jessica Mahy, Nicholas Taylor, Karen Dodd, La Trobe University, AUSTRALIA

027 BS Q121

Less than 10% of adults with Down syndrome are estimated to participate in the recommended levels of physical activity. This places them at an increased risk for development cardiovascular disease, obesity and diabetes. Understanding the barriers and facilitators to their participation in activity is important to help design interventions to increase their levels of activity.

To identify facilitators and barriers to physical activity for adults with Down syndrome.

A qualitative research study using semi-structured interviews was conducted. A purposive sample of 18 participants (3 male, 15 female) was recruited through two agencies that provide services for adults with Down syndrome. The participants included 6 adults with Down syndrome, 4 parents and 8 day programs employees. The interviews were recorded, transcribed verbatim and coded by two researchers, independently.

The three main facilitators of activity indentified were: access to a support person, that the exercise was fun or had an interesting purpose, and, routine and familiarity. The three main barriers to activity were: lack of support, not wanting to exercise, and, medical and physiological factors.

The results suggest strategies to maximise facilitators and minimise barriers be employed to increase the activity performed by adults with Down syndrome. The vital role of support people was highlighted, as was the importance of incorporating both structured and unstructured forms of activity into the lives of adults with Down syndrome to maximise the opportunities they have to be active.

The Level Of Physical Activity In Irish Children With Down Syndrome

Nora Shields, School Of Physiotherapy, Division Of Allied Health, La Trobe University, Melbourne, AUSTRALIA; Juliette Hussey, Discipline Of Physiotherapy, School Of Medicine, Trinity College Dublin, IRELAND; Joan Murphy, Department Of Paediatrics, Trinity College Dublin, IRELAND; Joh School Of Physiotherapy, AUSTRALIA

028 BS Q121

It is recommended that children with Down syndrome (DS) engage in 60 minutes of moderate or vigorous physical activity (MVPA) daily. There are currently no data on the MVPA undertaken by Irish children with DS.

To complete a pilot study that examined if Irish children with DS met the recommended levels of MVPA.

23 children with DS (12 boys, 11 girls; mean age 12.2±3.5yrs) wore tri-axial accelerometers (RT3) for 7 consecutive days. The output from the accelerometer was converted into activity counts per minute that represent the amount of MVPA activity performed.

The average daily MVPA undertaken by the participants was 72.3±37.3 min. The average daily vigorous activity was 10.1±9.3mins. Only 4 children (19%) met the recommendations. There was a significant inverse association between MVPA and age ($r=-0.69$, $p<0.01$). The average daily MVPA of younger children (7-12 years; $n = 9$) was 97.3±36.9 min, and of older children (13-17 years; $n = 12$) was 53.5±25.4 min. The mean difference between the groups was significant (44.0 min, 95% CI 15.4 to 72.1 min, $p < 0.01$). There was no significant difference in MVPA between boys and girls (0.5 min, 95% CI -34.4 to 35.5 min). The time each child spent daily in MVPA varied considerably (coefficient of variation=51.6%).

Older children with DS perform significantly less MVPA than younger children with DS, and on average, do not meet the recommendations. This information is important for those who work with this group and are in a position to implement behavioural change.

Treadmill Training And Infants With Down Syndrome: Results And Procedures

Dale A Ulrich Center For Motor Behavior & Pediatric Disabilities, University Of Michigan, USA

029 BS Q121

Historically, the average age of onset of independent walking in infants with Down syndrome has been 24-28 months. Over the past 20 years, early interventions have not been very successful in reducing this delay. Onset of walking facilitates the onset of many other critical skills in the cognitive, social, and language domains.

To summarize the results of 2 randomized clinical trials involving treadmill training and infants with Down syndrome. To present a summary of important procedures that can be used by professionals and parents who are intersted in implementing treadmill training as a form of early motor intervention.

Two randomized clinical trials were implemented, each involving 30 infants with Down syndrome over the course of several years. beginning when the infant was about 10-11 months of age. Parents were trained how to implement the treadmill training in their home and researchers monitored the training on a monthly basis until the child could walk 3 independent steps.

On average, infants receiving treadmill training walked earlier (19 months) and with better walking gait. Infants receiving higher intensity treadmill training demonstrate more advanced ability to negotiate obstacles while walking and displayed a higher level of physical activity up to 6 months after treadmill training ended.

Treadmill training is an excellent supplement to early motor training provided in physiotherapy. Any treadmill can be used assuming the belt speed is slow (.15-.20 meters/second). Parents and professionals must acquire some basic procedures to help the child step on the treadmill.

Skinny Alympiks ...Fighting Obesity Among People With Down Syndrome

Callaghan D., Down Syndrome Society Of South Australia Inc., Herbert A., Skinny Alympiks, Hughes A., Leveda Inc., Down Syndrome Society Of South Australia Inc., AUSTRALIA

030 BS Q121

Skinny Alympiks is a collaborative action research project between the Down Syndrome Society of South Australia, Skinny Alympiks & Leveda Inc. involving 20 adults with intellectual disability (80% adults with Down syndrome) who are morbidly obese. It is an innovative program addressing the alarming incidence of obesity in the population of people with intellectual disability.

The project is funded by the Australian Federal Dept. of Health - $200,000 for 18 months.

Our Vision:

Through research and education, we aspire to promote an understanding of the causes of obesity in people with an intellectual disability and contribute to the development of innovative programs that support the prevention and treatment of the disease.

Our Mission Statement:

To promote individualised nutrition and fitness strategies that assist people with an intellectual disability to maintain healthy lifestyles and healthy weight.

The program includes nutrition workshops that aim to teach participants to:

- identify the five food groups and the minimum daily requirements from each group;
- identify and read nutrition labels;
- identify fat/sugar and fibre content of products;
- identify low fat/sugar alternatives;
- write balanced menus using the Australian Guide to Healthy Eating.

We promote an active lifestyle for participants which includes funded access to individual fitness programs/trainers, information about fitness activities participants can become involved in the community.

We provide Case Management. This maximises the use of resources and provides ongoing support for participants and carers.

This presentation will report the results of 12 months implementation of the project.

Can We Teach Youth With Down Syndrome To Ride A Two Wheel Bicycle? Yes we can

Dale A Ulrich, Megan Macdonald, Joe Hornyak, MD, & Angela Argento, MD, University Of Michigan, USA

031 BS Q121

Youth with Down syndrome are physically less active than children without Down syndrome. Physical inactivity is associated with poor health conditions beginning in childhood. Current data suggests that less than 10% of youth aged 8-15 years who have Down syndrome can ride a two wheel bicycle. Most parents give up training their child after several years and keep the training wheels on the bicycle.

To summarize the results of two studies involving bicycle training and youth with Down syndrome implemented over a 5 day period. To summarize important procedures for parents and professionals to use who are interested in training youth with Down syndrome to ride a two wheel bicycle.

In the first study (n=61), we employed a randomized design where half of the participants aged 8-15 years were assigned to the experimental bicycle training group and half were assigned to the control group that received bicycle training the following year. The training was implemented for 75 minutes each day for 5 consecutive days. The second study was a descriptive study involving youth with Down syndrome (n=27) and youth with autism (n=31) aged 9-18 years.

56% of the riders in the first study learned to ride a two wheel bicycle while none of the control group learned. In the second study, 56% of the riders with DS learned to ride at a higher level of riding skill.

The majority of youth with Down syndrome can learn to ride a two wheel bicycle in a reasonable amount of time once fear is eliminated.

The Importance Of Fair And Balanced Information In The Prenatal Setting

Flint, K, Executive Director, Canadian Down Syndrome Society, Canadian Down Syndrome Society, CANADA

032 BS Q120

The Canadian Down Syndrome Society (CDSS) advocates for informed prenatal decision making based on complete, non-prejudicial and accurate information about Down syndrome. This session will address how partnerships must be formed between advocacy NGO's (such as the CDSS) and the professional bodies that are primarily responsible for the "quality" of care in delivery of non-prejudicial and accurate information to families. Working with the organizations that represent the professionals (Society of Obstetricians and Gynecologists and The College of Family Physicians of Canada, Canadian Association of Genetics Counselors, as

Canadian examples) is key in changing the culture and language that is used in the prenatal setting. The use of language and the practices of primary care medical professionals have a profound impact on the prenatal decision-making process of women and their families. The CDSS believes that fewer prospective parents would choose to terminate their pregnancies if the information provided to them did not intentionally or unintentionally place negative value on Down syndrome. The CDSS is working to develop tools that will educate practitioners in the use of value-neutral language when delivering information about Down syndrome to expectant and new parents. These tools will assist medical professionals to provide truly non-directive information rather than out-of-date stereotypes, and allow parents to make genuinely informed decisions. This session will present these tools in development and provide an opportunity for contribution and dialogue with medical professionals and parents.

Informing Parents Of Their Baby's Diagnosis Of Down's Syndrome-How Are We Doing?

Dr. M. Schwager, Dr.D.N.Carroll, Dr.P.Midgley, Dr. P.D.Jackson, University Of Edinburgh, Childrens Services, UK

033 BS Q120

Informing parents that their newborn baby has Down Syndrome (DS), requires experience, preparation, and interpersonal skills.How parents are told can influence how they come to terms with their baby's diagnosis.

To document how parents in one Scottish Neonatal Unit viewed how they were informed of their baby's diagnosis of DS. To compare these responses with those found in the literature, and consider ways to improve the experience.

44 babies with DS born 1998 - 2002 were identified from annual obstetric screening reports and cross- referenced with the Cytogenetic laboratory.

24 parents were contactable and agreed to participate. They were interviewed in person and a questionnaire completed.

Parents are more likely to have suspicions raised with them by a junior paediatrician (45.8%), or a midwife (25%).

59% of mothers suspected 'something was wrong' before being told.

91.4% of parents were told within 24 hours, both parents being present (87.5%), their baby present (90%), and a midwife known to them present (54.2%).

Who gave diagnosis? Consultant Paediatrician (45.8%), Junior Paediatrician (33.3%).

Parents found information supplied to be 'adequate'(83.3%),and 'realistic'(77.3%)

Parents' views on how they were told are more positive than reported previously.

Ideally the person sharing the information should be known to parents, knowledgeable about DS, and readily available. The location should be private, with both parents present with their baby.

Getting conditions right seemed more important than speed of information sharing.

Junior doctors and midwives are often in the 'front line' and additional training and support for them should be provided.

Prenatal Testing, Down Syndrome, & What To Do For Future Generations

Mark W. Leach, Down Syndrome Of Louisville (USA), USA

034 BS Q120

Prenatal testing advances are outpacing medical practitioners' and society's awareness of the positive developments for living a life with Down syndrome. Without purposeful efforts to improve informed decision making, future generations will have fewer babies born with Down syndrome. This presentation will provide some best practices, resources, and materials for providing balanced information in the prenatal testing context.

- To educate about current prenatal testing techniques.
- To inform about the impact of universal prenatal testing programs.
- To share resources for improving informed decision making about prenatal testing.
- Research was conducted into prenatal testing techniques.

Medical journals and news reports were surveyed concerning physicians' knowledge about prenatal testing and Down syndrome, and the effect of universal screening programs.

Mr. Leach has presented at local, regional, national, and international conferences on prenatal testing and on Down syndrome. The presenter leads a task force in the United States devoted to sharing and improving materials and techniques for medical and societal outreach to raise Down syndrome awareness.

Participants will be better educated on existing and planned prenatal tests. They will have a greater awareness about the impact of prenatal testing. Each will leave with resources they can access for providing improved informed decision making about prenatal testing.

As currently practiced, prenatal testing will reduce the number of individuals with Down syndrome in future generations. This is due, in part, to outmoded views about Down syndrome. Providing accurate, balanced information is needed for a responsible prenatal testing program.

Family Leadership

Annette Mayer, Parent To Parent Queensland, AUSTRALIA

035 BS Q120

Who knows our sons or daughters better than us as parents? Who other than us parents have the emotional stake in the meaningful futures of our sons or daughters? Parent or Family leadership is the guidance that we are able to give to others who support our sons and daughters.

Family leadership is knowing what's important to and the gifts and capacities of our sons and daughters and having expectations that others who support them will do so in a person centred manner. Family leaders guide others to learn and understand Person Centred Practice.

There are a series of tools that we use with our sons and daughters to help figure out those things that are important to them and how best to support them. These tools create a plan that enables others to know and understand our sons and daughters and to give them meaningful support.

Having family members as leaders results in a desirable future for their sons and daughters, meaningful support from others, having and receiving person centred expectations from organisations in self direction and control and systemic changes that will benefit all people who have Down syndrome.

Families have the responsibility long term in providing support and care for their family members with Down syndrome. Family leadership skills can assist in the preparations to ensure that our sons and daughters have their desirable future and their needs and wants are respected for when we as parents are no longer around to do so – succession planning.

Reproductive Decision-Making In Families Of Children With Down Syndrome

Van Riper, M., University Of North Carolina At Chapel Hill, USA

036 BS Q120

Reproductive decision-making generally becomes much more complex in families once they have given birth to a child with a genetic condition. The question of whether or not to have additional children often takes on new meaning, as does the decision to undergo prenatal screening. Currently, we have limited information about reproductive decision-making in families of children with Down syndrome.

The purpose of this presentation is to describe reproductive decision-making in families who already have one child with Down syndrome.

Five stories from an ongoing program of research which has included over 400 families living with Down syndrome will be presented.

The stories to be presented were purposefully selected because they vividly illustrate the complexity of reproductive decision-making in these families. Moreover, they show that these decisions are rarely autonomous decisions based solely on the needs and preferences of the parents. Rather, they are socially situated decisions. While many families decide to have one or more other children, the decision to undergo prenatal testing is often a difficult, stress-producing decision. This is especially true for families who feel pressured to undergo prenatal testing.

Currently, there is an urgent need for more dialogue between families of children with Down syndrome and their health care providers concerning reproductive decision-making. Health care providers need to recognize that each family is unique. What is an easy decision for one family may be a very difficult decision for another family. The key is that health providers need to listen.

Developmental And Behavioural Disorders In People With Down Syndrome Aged 8-18 Years

Miguel Palha MD, David Andrade MD, Mónica Pinto MD, Portuguese Down Syndrome Association/Child Developmental Centre Diferenças, PORTUGAL

037 BS QG21

Individuals with Down syndrome are predisposed to show a specific behavioural phenotype, or a pattern of strengths and challenges in functioning across different domains of development. People with Down syndrome are likely to exhibit various behavioural and emotional disorders, the prevalence of which has not been fully acknowledged.

Identify and demonstrate the incidence of developmental and behavioural disorders in individuals with Down Syndrome (8-18 years old).

300 participants, aged between 8 and 18 years, were assessed by a developmental paediatrician. Development and behavioural individual characteristics were assessed, namely, cognitive function, language skills and motor development. In selected cases, Cognitive Function was assessed using WISC III R; Language by EEL; and Adaptative Behaviour by PEDI. DSM IV TR was used for diagnostic criteria.

The incidence of cognitive impairment was 99,66%; Specific Language Disorder: 52%; Autism Spectrum Disorder: 9%; ADHD: 9,66%; Oppositional Defiant Disorder: 0,33%; Conduct Disorder: 0%; Major Depression: 6,7%; Anxiety Disorders: 4%; OCD: 6,33%; Tics Disorder: 14%; Stereotyped Movement Disorder: 13,66%; and psychotic disorders: 0,33%. Moreover, seven different developmental/behavioural patterns were identified and will be described.

Previous studies have reported a specific behavioural phenotype associated with Down syndrome. Until recently, however, little attention has been given to identify this behavioural profile and the importance of differential diagnoses. Behavioural and developmental disorders are very frequent in Down Syndrome. The authors will provide a theoretical framework to help developmental paediatricians to identify developmental and behavioural disorders in individuals with Down Syndrome.

Behavior Problems And Maternal Mental Health Problems In Children With Ds, Autistic Children, Non-Intellectually Disabled And Other Intellectually Disabled Children

M. Amirimajd (Islamic Azad University, Abhar Branch) And S. Faramarzi (University Of Isfahan), Islamic Azad University, Abhar Branch, IRAN

038 BS QG21

Children with DS and other children with intellectual disability are at heightened risk for behavior problems. This dual diagnosis may affect their mothers.

The present study investigates the occurrence of behavior problems and maternal mental health problems in different groups of children.

A cross-sectional study of 135 children was undertaken in Iran.We examined behavior problems of 30 children with DS, 29 autistic children, 40 children with an intellectual disability other than DS and 36 non-intellectually disabled children and impact of intellectual disability and behavior problems on their mothers. Data were collected using Child Behavior Questionnaire for completion by teacher, Child Behavior Questionnaire for completion by parent, General Health Questionnaire and Demographic Questionnaire.

Results showed that autistic children showed the most behavior problems and children with DS showed less behavior problems relative to other children with intellectual disability but more than normal children. Children's behavior phenotypes were related to mother's mental health. Mother's anxiety symptoms and sleep disorder predicted children's total behavior problems, hyperactivity- aggressiveness, and attention deficit. Mother's depression symptoms predicted children's anxiety-depression.

SES, sibling constellation, and mother's age & education were not related to children's behavior problems and mother's mental health.

Results suggest that children with DS show less behavior problems than other children with disability. Regression analyses revealed that the extent of child behavior problems was a much stronger contributer to mental health problems than was the child's intellectual disability. The discussion focuses on implication for service provision to families of children with intellectual and behavior problems.

Building On Family Strength And Resilience - A Practitioner Review

Dr Grainia Clarke, St Michael's House, IRELAND

039 BS QG21

Over time our understanding of people with Down syndrome and their families has both developed and become more refined, resulting in ongoing service developments.

This series of papers and linked discussions lead by psychologists from St Michael's House highlight developments in the field over recent times. The aim of the papers and discussion is to present original research, reviews of the relevant literature and individual case studies to emphasise the role of research in guiding service developments alongside the diversity of needs among individuals with Down syndrome and their families.

Recommendations are that services and practitioners develop more individualised approaches that take accounts of and reflect the heterogeneity of this population.

Over recent years, the impact on families of having a child with a disability has come to be seen in a more positive light. For example researchers are now asking questions, which highlight strength and resilience rather than those, which lead to a focus on parental stress and family adjustment difficulties. It is also clear that children with Down syndrome are not a homogenous group - nor are their families, and models of practice need to be able to adapt to individual differences.

This paper reviews the general literature and research on family resilience from a systemic perspective and questions the extent to which this body of knowledge is useful when working with families where a member has Down syndrome. The paper puts forward a model of practice aimed at promoting family resilience and enhancing the psychological well being of all family members, in a supportive, non pathologising and inclusive manner.

Fathers Of Children With Down Syndrome - A Research Study

MacDonald, E, St Michael's House, IRELAND

040 BS QG21

From a family systems perspective, intellectual disability (ID) affects the whole family, and thus professionals are better able to meet the needs of the child with an ID when working in partnership with all family members. However, both research and clinical practice have focussed unevenly on family members of children with ID, with less engagement with fathers. This has resulted in a lack of empirical studies which investigate father well-being and child-involvement. The present study aimed to contribute towards our understanding of paternal psychological adaptation and wellbeing by investigating process variables (acceptance and active avoidance) among fathers of children with Down syndrome.

Method Questionnaire data were gathered from 57 fathers of children with Down syndrome. In addition to measuring the child's behaviour, several father-related variables were measured - acceptance and active avoidance; mental health; positive perceptions of the child; and satisfaction with the parenting couple relationship.

Results Fathers who reported higher levels of acceptance also reported lower levels of stress, anxiety and depression. This group of fathers also reported higher levels of rewards gained from parenting their child. However, fathers who reported higher levels of active avoidance also reported higher levels of stress, anxiety and depression; and dissatisfaction with the parenting couple relationship.

Conclusions The findings suggest that acceptance and active avoidance may play significant roles in fathers' psychological adaptation and psychological wellbeing, and that further research is needed to extend the growing evidence of the efficacy of direct stress interventions with families of children with Down syndrome, including a new wave of psychological therapies using principles of Acceptance and Commitment Therapy, and mindfulness based cognitive therapy.

Autistic Spectrum Disorders In Down Syndrome

Colin Reilly, St Michael's House, IRELAND

041 BS QG21

There are now a substantial number of studies to demonstrate that a subgroup of individuals with Down syndrome meet the diagnostic criteria for an Autistic Spectrum Disorder, and as a result are likely to need qualitatively different approaches in terms of supports and interventions to maximise their educational potential and quality of life. This paper discusses the prevalence, manifestation of symptoms, and correlates of ASDs in Down syndrome based on a comprehensive review of the literature. Issues regarding the diagnostic assessment of ASDs in Down syndrome are also highlighted. Reference is also made to the experiences of families of affected children, and recommendations for appropriate interventions for this population are discussed in the light of current research.

The Changing Nature Of Support Across The Life Cycle: Learning From Research; Learning From Practice

Dr. Grania Clarke, Elaine Macdonald, Colin Reilly, St Michael's House, IRELAND

042 BS QG21

Like all families, those with a member who has Down syndrome face different challenges across the lifecycle and at transition points in particular. This paper and discussion will look at some of the key lifecycle challenges that can face both individuals with Down syndrome and their families. The multiple contexts in which the individual and the family exist will be examined and best practice guidelines will be proposed for the level and type of support needed for individuals, schools, support services, and for families themselves. Clinical examples of individuals and their families will be used to illustrate some of the challenges faced and how interventions can be responsive and useful in such contexts.

Moms Only

May Gannon, Dr Mercedes Egan & Annette Mayer, IRELAND / AUSTRALIA

043 BS QG22

The Moms Only is designed to facilitate reflection and discussion between mothers of children with Down Syndrome. Issues and topics will be guided by the needs of the participants, to allow for dialogue between mothers, to give encouragement to each other and to share experiences, successes, failures and strategies.

The session will be facilitated by May Gannon, Counsellor, psychotherapist and drama therapist DSI and Dr Mercedes Egan, Director of the Early Services Kildare

Grandparents Only

Pascale Claes, FRANCE / IRELAND

044 NS HG17

The Grandparents Only is designed to facilitate reflection and discussion between grandparents of grand-children with Down Syndrome. Issues and topics will be guided by the needs of the participants, to allow for dialogue between grandparents, to give them space to talk about their feelings and emotions and allow a platform for encouragement to each other and to share experiences, successes, failures and strategies.

The session will be facilitated by Pascale Claes.

Social And Emotional Development Of Young People With Down Syndrome

Trevor R. Parmenter, Stewart Einfeld University Of Sydney; Bruce Tonge, Monash University, Centre For Disability Studies University Of Sydney, AUSTRALIA

045 NS HG20

This paper reports the results of an Australian study of the behavioural and emotional problems of a subset of 72 people with Down syndrome from an epidemiological longitudinal study of a group of over 850 young people with an intellectual disability.

The aims are to study the biological, psychological and social factors that help or hinder the optimal development of young people with an intellectual disability.

The study commenced in 1989 with four yearly data collection points This paper reports on findings from Time 1 (1992) to Time 4 (2004) and more recent data from Time 5 (2008). Data include main day time activity, social networks, social adaptation, and behavioural and emotional disturbance.

Despite the ideals of normalisation and inclusion, young people with Down syndrome are mainly not independent of their families and are generally not working outside disability services. The family provides the majority of social contacts. Compared to other people with an intellectual disability, people with Down syndrome had fewer problems, were less disruptive, engaged in fewer self-absorbed behaviours, were less anxious and had fewer social relating problems. They scored significantly higher on self talking or talking to imaginary others. Whilst there was a decline on all measures of behavioural disturbance over a 12 year period for all people in the study, depression scores for people with Down syndrome did not decline.

Results indicate the need for greater emphasis upon widening the social networks of young adults with Down syndrome. Depression is an issue worth monitoring.

'Self-Talk' - What's It All About?

Judy Opolski, Flinders University/Down Syndrome Society Of SA, AUSTRALIA

046 NS HG20

Self-talk is extremely common in people with Down syndrome " anecdotal and limited research evidence suggest that the majority, young and old, talk aloud to themselves, objects, toys or imaginary companions. However, concerns are sometimes felt by families and others about it's appropriateness.

This study aimed to collate data about the prevalence, frequency, type and function of self-talk; to explore whether self-talk is influenced by a number of variables; if it changes over time; and how it is viewed by families.

Data were gathered via a questionnaire sent to families who had a son/daughter with Down syndrome aged 8 - 35 years. Eight families were followed up with interviews to obtain more detailed data.

104 families returned the questionnaire. 98% of the respondents reported that their child used self-talk, with over 70% self-talking 'several' or 'many' times a day. No differences were found in the frequency or types of self-talk across a range of variables. Most parents considered self-talk to be a useful tool for their child and were not overly concerned about the behaviour.

A variety of functions were identified including: self-regulation, debriefing, decision making, moral reasoning, fantasy/entertainment. Diverse forms of self-talk (monologues, dialogues, commentaries, role-playing etc) were revealed. Considerable individual differences were apparent, and the data suggested that changes to the type and function of self-talk are common over time.

This study found that self-talk is extremely common, generally considered to be developmentally appropriate, and fulfils a variety of very useful functions for people with Down syndrome.

Self-Talk In Children And Adults With Down Syndrome

Paul J. Patti, New York State Institute For Basic Research In Developmental Disabilities, USA

047 NS HG20

Many children and adults with Down syndrome have been observed to engage in self-talk to work out situations, express their inner feelings, and to entertain themselves.

The Self-Talk Survey was developed to investigate the quality, style and content of self-talk behaviour.

To obtain a diversity of respondents, the survey was distributed to families in parts of Canada, the United Kingdom and the United States.

Parent/carer ratings revealed that self-talk was present in over 75% of the survey sample. Age and level of disability did not influence one's ability to engage in self-talk. Ratings revealed that self-talk was generally understandable, in a normal tone of voice, and does not occur only when the person is alone. A person's self-talk was typically directed to them self, but could also involve a real or imaginary person, or a favourite toy or object. The content focused on a recent or expected event, a favourite television program or movie, family or friends, completing an activity, or complaining about someone or something.

Survey findings supported the perception that a high percentage of people with Down syndrome engage in self-talk and this behaviour is independent of age. Self-talk can be an outlet for planning or rehearsing an action, working out a problem, or be a self-dialogue about something interesting or important. Self-talk is not unique to people with Down syndrome, and it is necessary to study the character and content of this behaviour among people with other intellectual or developmental disabilities for any qualitative differences.

Down Syndrome In Association With Mental And Physical Illness

Pauline Stewart, SPAIN

048 NS HG20

I will talk about people with Down syndrome and their associated illnesses; Post Traumatic Stress and Immune Deficiency.

Through it all they have survived to become the wonderful people that they are and have taken their place in society. To be aware that Down Syndrome and associated illnesses are separate, and have to be treated as such.

Presentation, feed back, questions and answers; 1) Posters; 2) Photos; 3) the survivors story, (in pamphlet form); to be given to professionals and non professionals

1) Better understanding of the difficulties that people with Down Syndrome have when they have associated illnesses.

2) Be more sympathetic

3) When a person with Down syndrome is presented to them with an associated illness they will not say it is "Because he/she has Down Syndrome".

4) That the non professionals and Mams and Dads will not give up and they will continue to find the help they need to help the children with Down Syndrome and their associated illnesses.

Conclusions: That associated illnesses as being separate from Downs Syndrome and not part of it.

Recommendations: That changes will be made to the way they perceive Down Syndrome associated illnesses.

The Physical And Mental Health In Mothers Of Children With Down Syndrome- What Makes A Difference?

Bourke, J; Ricciardo, B; Bebbington, A; Aiberti, K; Jacoby, P; Dyke, P; Bower, C; Leonard, H, Telethon Institute For Child Health Research, AUSTRALIA

049 NS HG20

A comprehensive questionnaire was sent to the parents of children and young adults with Down syndrome (DS) in Western Australia aged up to 25 years in 2004. Of the 500 families contacted and invited to participate, 363 families completed the questionnaire (72%) of which 250 were mothers.

The objective of the Down Syndrome NOW study is to identify major issues facing children and young adults with Down Syndrome and their families in Western Australia.

The mental and physical health of the mother was evaluated using the SF12, which estimates the two summary scores Physical Component Summary (PCS) and Mental Component Summary (MCS). Univariate analysis, using each score as an outcome measure, investigated child characteristics such as age, gender, specific health conditions, number of episodes of illness, behaviour, communication and functioning ability. Multivariate analysis included maternal and family characteristics such as maternal age, income, marital status, maternal education and measures of family functioning.

The physical health of the mother was affected by a number of child factors including ongoing health conditions and child's BMI, whilst many more factors influenced the reported mental health of the mothers. These included gender, episodes of illness, a number of challenging behaviours and how independently the child is able to function.

Families with a child with Down syndrome face many issues and stressors. Understanding specific factors that may contribute towards better mental or physical health of the mother can help identify areas for improved support for families.

The Prevalence Of Attention Deficit/Hyperactivity Disorder (Adhd/Add) Among Children With Down Syndrome

Edvardson Shimon, Musallam Nadira, Tenenbaum Ariel, Pediatric Dept. & Neuropediatric Unit At Hadassah University Medical Center; Head, Down's Syndrome Medical Center, ISRAEL

O50 NS HG20

The prevalence of Attention Deficit/Hyperactivity Disorder (ADHD/ADD) among children with Down syndrome is unknown. This is somewhat surprising in view of the increased prevalence of ADHD-symptoms among children with intellectual disabilities in general.

In the past it was thought that behavioral disturbances were inherently linked to cognitive impairment in persons with mental retardation, thus obviating the need for further consideration.

The term 'dual diagnosis' refers to a person with both mental retardation and a psychiatric disorder and it is now generally accepted that such a combination exists and has meaningful therapeutic implications.

To determine the prevalence of ADHD/ADD among children with Down's syndrome attending the Down's syndrome medical center in Jerusalem, Israel.

We screened a population of children aged 5 years and older with Down's syndrome for ADD/ADHD enrolled in the referral Down syndrome medical center at the Hadassah-Hebrew university medical center in Jerusalem, Israel.

85 families were approached. 2 families declined to participate. 25 (29%) fulfilled DSM-4R criteria for ADHD/ADD. 16 of these children (64%) were diagnosed as predominantly inattentive type. 4 (16%) were predominantly impulsive-hyperactive and 5 children (20%) had the combined subtype. Correlations between ADHD/ADD-diagnosis and concomitant thyroid, heart or obstructive sleep problems was investigated. We will also present our experience in treating ADHD/ADD with stimulants among children with Down's syndrome.

We believe that ADHD/ADD is underdiagnosed among children with Down syndrome. Screening for ADHD/ADD among these children may result in early diagnosis and improvement in learning achievements.

A Journey Of Life And Independence

Graham & Annette Mayer, AUSTRALIA

O51 NS HG23

Tammy is our daughter who after many challenges in life is happily married to a wonderful man Dan, and is living independently in our hometown of Toowoomba, Australia. Tammy and Dan both have Down syndrome. This is their story.

We will endeavour to share the journey that as a family we have taken to get to where we are today. There have been many laughs, fears, obstacles and challenges thrown at us and we have thrown at ourselves along the way.

We have used Person Centred Planning tools within our family as well as facilitating Person Centred Thinking workshops to other people so they can feel part of the journey without the many fears they had. We will share our tools and stories.

Tammy and Dan are very happy and live together like any other couple, with a few added supports. As most parents would, we have had to face our own fears and insecurities about the life they have and had to find ways to support each other and the rest of the families during this wonderful journey.

Tammy and Dan have a great life. They demonstrate to others that people with Down syndrome in our home town are more than capable of doing what every one else does given the right support and opportunities. This is their story.

Down Syndrome NOW: Research Lessons We Have Learned As Parents Involved In Research

Julie Ireland & Jackie Softly, Parents & Staff Of Down Syndrome Western Australia, Down Syndrome Western Australia, AUSTRALIA

O52 NS HG23

This paper examines the involvement of parents in the recent Down Syndrome NOW (Needs Opinions Wishes) research conducted by the Telethon Institute for Child Health Research in Perth, Western Australia.

To explore the lessons we learned regarding consumer involvement in research, to encourage other families to get involved and to enhance future research to help achieve the best outcomes for people with Down syndrome and their families.

The research collected considerable data related to the health, educational, social and functional aspects of living with Down syndrome. More than 360 families (73% of the population for the target age group) had input to the study. Parents were involved during the formulation of the survey, data collection, and developing the first summary report.

By comparing the level of involvement that occurred with documented best practice models of consumer involvement we were able to identify areas where researchers and consumers 'could do better ' in future research.

The involvement of parents in conducting the study added a valuable dimension to the research process, outcomes and accessibility of the reported data; however, with planning, improved collaboration and greater recognition of the value of consumer involvement this could have been enhanced. The experience has provided valuable learning for both the researchers and parents and this examination of consumer participation has led to a stronger partnership and increased consumer involvement in other studies.

The Value Of Parent To Parent Support

Sue Robins And Mike Waddingham, Edmonton Down Syndrome Society, CANADA

053 NS HG23

This presentation will highlight the benefits of having peer support offered to parents when their baby is first diagnosed with Down syndrome. We will include specific information about the successes and challenges of the Edmonton Down Syndrome Society's volunteer-run Visiting Parents Program, which has been in existence for four years in Edmonton Alberta Canada.

The philosophies behind the value of parent-to-parent support will be explained, including the importance of hope and the crucial aspect of connecting parents up who have walked similar paths. Research will also be shared on the topic of peer support.

The presentation will provide statistics on the Visiting Parents Program, including numbers of in-person visits, the New Parent Package program, and presentations given to health care professionals to garner understanding and referrals. The training for the volunteer Visiting Parents Team will be discussed.

Both the successes and challenges will be outlined.Successes include the number of in person visits, feedback from visited parents, and involvement of the visited parents in the society. Challenges to the program are obtaining referrals from social workers and other clinicians, reaching the multi-cultural community, and fostering a relationship with the Genetics Clinic to connect with parents with a prenatal diagnosis.We will also talk about the challenges to our team of visits involving prenatal diagnosis and adoption.

We will present the nuts and bolts of setting up a Visiting Parents Program in our presentation. The talk will emphasize the power of having a grassroots, community-based program, and will be realistic in the challenges involved with working with the health care community.

Parents Of Down PoD Consortium

Liana Vislan, ROMANIA

054 NS HG23

PoD is an education tool (DVD, CD and book) with relevant information for parents of children with Down Syndrome. The consortium has done a research on topics such as education, sanitary services, funding and social helps, etc in order to answer those questions parents may have.

To answer questions of parents in three stages:

- Down syndrome in 0 to 6 years old
- Down syndrome in 6 to 18 years old
- Down syndrome in adulthood.

Development of a DVD, CD and a book with relevant information.

An educational tool for parents and professionals.

Down Syndrome School Behaviour Clinic

Dr Philip Mattheis, USA

055 NS HG23

Behaviour problems are common for children with Down syndrome (and those who know them). This is particularly true in school, and often to the point of interference with academic progress and peer interactions. At our Down Syndrome centre in Cincinnati, Ohio, USA, we hold a weekly clinic for students with Down syndrome who have behaviour issues at school, with a multidisciplinary approach that includes Speech/ Language Pathology and Education consultants. As we attempt to identify the factors driving the problem behaviour, we find that while communication is often a key feature in understanding the problems, the solutions usually require close collaboration with school personnel and other community resources to change school programming and expectations. Changing the child is much more difficult.

Common categories of problems will be presented, with discussion of the array of solutions that may be available to address causes, and to improve outcomes.

Obviously, our experience reflects local, regional, and national policies and laws, but should provide useful starting point for comparison and contrast with other settings.

Facilitating Speech And Language Therapists In Training Through A Real Life Case

Clare O'Shaughnessy, NUI Galway, IRELAND

056 NS HG22

The four-year B.Sc. in Speech and Language Therapy programme at NUI, Galway commenced in February 2003. Within the third year of the course students complete a module on communication and cognitive impairment. The core aim of the programme is to provide high quality, integrated, transparent modules which provide speech and language therapists (SLTs) in training with a clear pathway to becoming a competent clinician.

The aim of the module was to provide the SLTs in training with an opportunity to apply theory to practice in the university setting with support from academic staff.

24 SLTs in training worked in groups of eight to formulate a Life Plan for a real life case for her parents. The case was a preschool girl with Down Syndrome. Her mother provided detailed case history information, a team report and two 15 minute video clips of the child. The child's mother and each groups provided written feedback on their learning experience.

The SLTs in training learnt how to problem-solve and developed their ability to integrate theory with practice. All groups and the parent reported that they learnt a lot and found the topic interesting and helpful. The students enjoyed the true life scenario and thinking practically about the case. They learned that there is "a lot to take into consideration in DS". The parent reported that "all children should have a life plan" and that she now "felt equipped with knowledge in advance" and "prepared for meetings with professionals". She felt "well-informed and confident".

It provided an example of using real life cases in the academic setting and transferring student knowledge to the community.

A National Strategy For The Development And Delivery Of Speech Language And Communication Services: Increasing Provision Through The Co-Worker Network And Other Initiatives

Baksi, L. & Colleagues, Symbol Uk Ltd, UK

057 NS HG22

The 5 year strategy of Symbol UK Ltd and the Down's Syndrome Association was launched in 2005 and presented at the WDSC in Vancouver in 2006.

This presentation will describe progress made and further developments, focusing in particular on the co-worker network of specially training and supervised personnel to who deliver targeted intervention groups across the UK. The work of these co-workers is supervised by speech and language therapists with specialist skills in working with people who have Down's Syndrome and a parallel training programme supports this.

By summer 2009, three cohorts of co-workers will have completed training and infrastructure for the network has been significantly developed. This presentation will present data on the training itself and background of co-workers, the scope and reach of these services, and discuss the principles underpinning the project.

Targeting Speech, Language And Literacy Development In The Early Years

Julie Hughes & Rebecca Baxter, Down Syndrome Education International, UK

058 NS HG22

Children with Down syndrome usually have an uneven profile of social, cognitive and language development. They do not have a profile of equal delay in all areas and have a profile of strengths and weaknesses. Spoken language development is a particular area of difficulty for children with Down syndrome. There is now consistent evidence that these children have a profile of specific speech and language delay relative to their non-verbal mental age. However, focused interventions that address speech and language development can contribute to changes within this profile.

There is considerable agreement among international experts on the principles that should guide speech and language therapy for children with Down syndrome based on research into their difficulties and into effective interventions. All experts identify the need to have separate targets for the four components of speech and language skills : communication, vocabulary, grammar and speech work. The use of a sign system will promote spoken language, with benefits for both comprehension and production. Also, the use of reading activities to teach spoken language is an evidenced-based approach that benefits children with Down syndrome.

The speakers will cover topics such as promoting speech skills, receptive and expressive language development, when and how to introduce receptive and expressive grammar targets, and when and how to introduce reading to help promote language and speaking development. The workshop will also include demonstration of the DownsEd See and Learn materials.

This workshop will provide parents and professionals working with pre-school children with Down syndrome practical advice and guidance about information and activities to promote speech, language and literacy development.

Analysis Of Two Early Language And Literacy Programs For Young Children With Down Syndrome: A Pilot Study

Drs. Karen Riley & Gloria Miller, The University Of Denver, USA

059 NS HG22

The purpose of this project is to evaluate the effectiveness of two different language and emergent literacy intervention approaches for young children with Down syndrome. Although etiologically specific information regarding phenotypic profiles and developmental trajectories have exploded during the past decade there remains a paucity of randomized control studies examining strengths based intervention approaches for children with specific etiology. Children with Down syndrome have a specific, but fluid developmental profile that has been well documented in the literature. To date, however, this profile has not been utilized in intervention planning.

This project will document the effectiveness of two strengths-based parent delivered approaches: (1) Dialogic Reading, which capitalizes on the relational strength, and (2) See and Learn, which targets the visual spatial strength of children with Down syndrome.

Sixty children and families screened into the project will be randomly assigned to one of these two promising interventions or to a wait-list control condition. Growth curve modeling will be used to evaluate and contrast the effectiveness of each approach and to compare children's language and early literacy performance with children in the wait-list control condition.

Individual child profile patterns that correlate with the efficacy of either approach also will be presented. As both of these approaches are home based programs, perceptions of program effectiveness and changes in parental confidence and knowledge about early literacy activities will also be presented.

Findings from the pilot study as well as future directions for research and educational intervention will be provided.

Solution Focussed Brief Approach To Target Setting- Sharing Experience Of Working Together With Parents Of Children With Down Syndrome

Gilly Flanagan, The Children's Centre, UK

060 NS HG22

Parents are the uncontested experts on their children, yet Speech and Language Therapists do have particular expertise and experience to share.

This presentation explores how the Solution Focused Brief approach can be used with parents, to identify the most appropriate communication targets for young children with Down Syndrome.

Information will be provided about the process and experiences of using it will be shared.

To enable parents to identify the most appropriate targets for their child, emphasising achievements and strategies that they have already found useful.

The approach continues to be developed. Feedback and reflection show this to be a powerful approach that can achieve positive outcomes for the child.

Further study of the application of this approach would be beneficial.

A life spent making mistakes is not only more honourable, but more useful than a life spent doing nothing

George Bernard Shaw

It is a very sad thing that nowadays there is so little useless information

Oscar Wilde

Education is an admirable thing.
But it is well to remember from time to time
That nothing that is worth knowing can be taught

Oscar Wilde

Day Two

Friday 21 August 2009

Plenary lectures

Rooms of presentation are coded:
MH (MAHONY HALL)
TH (THEATRE)
BS AND CODE (BUSINESS SCHOOL)
NS AND CODE (NURSING SCHOOL)

Promoting Good Health

Promoting Good Health And Well-Being In Children And Adults With Down Syndrome

Professor Hilary Hoey, MA, MD, FTCD, FRCPCH (UK), FRCPI, MICGP, DCH, D Obs RCOG, Dept of Paediatrics University of Dublin Trinity College, National Children's Hospital Tallaght, Dublin, IRELAND

PL8 MH

The aims of health care for children and adults with Down Syndrome and their family are to achieve good health, good well-being and a good quality of life. Children and adults need a healthy life style including good nutrition and regular exercise together with health screening and care as recommended for the general population. It is well recognised that as a group they have a high incidence of treatable medical disorders. All studies show that early intervention carries a better outcome for their general health, quality of life and life expectancy. With medical progress many people with Down syndrome now live to old age.

Health care and medical management guidelines appropriate for children and adults with Down syndrome have been developed in many countries and health care requirements vary with age. In infancy and childhood these relate to general health, growth including height and weight gain, heart, thyroid and gastrointestinal disorders, cervical spine, vision, hearing, speech and psychosocial development and effective education. The health and well-being needs of adolescents vary and include the development of puberty and sexuality. Life expectancy among persons with Down syndrome is continuing to increase and health should be monitored throughout adulthood including mental well-being, behavior, intellectual and functional capabilities.

Every person with Down syndrome is unique and with good health and mental well-being they can lead a happy and fulfilled life.

Childhood Health

Dr. Liz Marder, Consultant Paediatrician, UK

PL9 MH

This session will focus on promoting health and well-being in children with Down's syndrome. I will discuss how this begins with an awareness of medical problems that may be associated with Down's syndrome during childhood, and the importance of surveillance programmes to identify problems early. I will present some of the work we have been doing in the UK to help increase awareness of these issues amongst health professionals, and to provide information for parents on health issues and the schedule of health checks they should expect. I will illustrate this using the cardiac guideline for medical surveillance for people with Down's syndrome developed by the Down's syndrome medical interest group (UK and Ireland).

Health Issues in Adolescents with Down syndrome

Joan Murphy RSCN MSc, Dip. Stats, PhD, IRELAND & Emmanuel Bishop - Self Advocate - Violin Recital

PL10 MH

Adolescence is an area of rapid change with significant physical, emotional and social development. In addition to the health needs of childhood the health and well-being needs of adolescents vary and we now find that puberty, sexuality, weight management and mental health wellness issues are more evident in persons with Down syndrome.

The challenge for healthcare professionals and parents is to identify and support the needs of each individual through these changes which are vital for developing their self esteem, personal identities and to understanding what having Down syndrome means for them as they prepare to enter adult life.

Identifying the specific effects of Down syndrome on development during this timeframe will put healthcare professionals and families in a better position to develop effective supports and appropriate interventions.

Nutrition & Lifestyle

Food, Feeding, Family. . .Freedom: the Keys to Building Healthy Lives

Joan Guthrie Medlen, RD, LD, USA

PL11 MH

Creating healthy lives for individuals with Down syndrome and their families requires a blend of science, education, creativity, and tenacity. This presentation touches on a bit of each illustrating the simple, yet complex task of promoting healthy eating and independence. The details of which will be shared in the afternoon, Meet the Expert Session.

Mental Wellness Adults & Ageing

Strengths and weaknesses of teens and adults with Down syndrome

Dr Dennis McGuire, Ph.D., USA

PL12 MH

Teens and adults with Down syndrome have a host of unique and interesting behavioural characteristics such as self talk, repetitious "grooves," visual (photographic-like) memory, emotional radar and sensitivity to others. These characteristics may be very beneficial but they may also be unproductive or too easily mistaken as mental illness by the uninformed. This plenary will clarify some of the productive and harmless behaviour from bona fide mental health problems and discuss ways and means to promote best possible use and understanding of these characteristics.

Sexuality

Relationships Require Skills

David Hingsburger M.Ed, CANADA

PL13 MH

Relationships do not happen because we put individuals with disabilities in the right settings, they occur because we have taught the right skills. Do you know the single

most important social skill for the maintenance of human relationships? You will after this session.

Supporting Best Vision, Communication, Language and Learning

Ensuring Best Possible Hearing

Mr Patrick Sheehan MB BCh, M.Phil., FRCSI, FRCS(Ed), FRCS(ORL-HNS), UK

PL14 MH

Hearing difficulties and other ear, nose and throat medical issues are relatively common in children with Down syndrome. This presentation will address the current best practice in managing the hearing loss associated with Down syndrome. Mr Sheehan will outline the NICE, the National Institute of Clinical Excellence (UK), guidelines. He will also touch on other ear, nose and throat conditions including sleep disordered breathing and reflux. There will be an opportunity to meet Mr Sheehan in the 'Meet the expert' session where he will be happy to answer specific questions from parents.

Promoting Clear Speech - Talk is cheap, speech is precious

Dr Clothra Ní Cholmain PhD, IRELAND

PL15 MH

This presentation will provide listeners with a brief overview of the role of speech in facilitating language development and language use for living in communities. It will identify some of the known constraints that those with extra chromosome 21 material may encounter en route to developing an effective and efficient spoken language system. The impact of these constraints on the developing and established phonology and language system will be explored. The presentation will conclude with a review of the possible and known impacts and outcomes of a range of intervention approaches on speech throughout the lifespan.

Key words: speech, language use, development, constraints

Supporting language and communication in persons with Down syndrome

Jean-A. Rondal, Emeritus Professor Of Psycholinguistics, University Of Liège, BELGIUM

PL16 MH

Language stimulation and intervention in persons with Down syndrome has to be conceptualized according to a life-span perspective. This does not mean that the same things should be done and repeated over the years. Early and continued intervention pursue different goals and need to be conducted differently according to age and developmental level: in babies, children, adolescents, young adults, adults, and aging persons with Down syndrome. The presentation will be devoted to specifying and justifying the basic principles and defining the major steps of such a live-span program for language and communication. For those interested in obtaining more detail on these issues and possibly some additional ones, there will be an opportunity in the session "Meet the Expert".

Ensuring Best Possible Vision

Professor M Woodhouse, Special Needs Optometry at Cardiff, UK

PL17 MH

Children with Down syndrome are 'visual learners' and yet they are at high risk of visual disorders than can have a detrimental effect on learning. Drawing on her research over the last 20 years, Maggie will outline the most common visual problems, and describe ways of overcoming the deficits.

Meet the Expert

Child Health

Dr. Liz Marder Consultant Paediatrician
with Dr Sheila Puri, Dr Monica Pinto, UK

ME6 MH

In the "Meet the Expert" session we will explore medical issues in more detail. We will consider guidelines developed in the UK, and Portugal and how they may need to be tailored to the needs of different countries or communities. We will also look at some evidence on how guidelines are being implemented and whether they improve care.

Additional contributions to the "Meet the Expert" session to include:

0129 Does audit & guidelines help improve the medical care & management of children with Down Syndrome? – Sheila Puri, Leeds UK

0133 Medical Intervention in People with Down Syndrome "Portuguese Guidelines"– Monica Pinto, Lisbon, Portugal

Adolescent Health

Dr Joan Murphy PhD
Professor Siegfried Pueschel, Professor Trevor Parmenter and Dr. Nora Shields
IRELAND, USA, AUSTRALIA

ME7 BS QG15

In the "Meet the Expert" session we will explore health issues in adolescents in more detail.

Additional contributions to the "Meet the Expert" session to include:

0130 Physical Activity in Adolescence – Dr. Nora Shields, Australia/Ireland

0131 Social & Emotional Supports in Adolescence – Professor Trevor Parmenter, Australia

0132 Adolescents & Development of Puberty – Professor Siegfield Pueschel, USA

Mental Wellness

Strengths and weaknesses of teens and adults with Down syndrome

Dr Dennis McGuire Ph.D., Director of Psychosocial services at the Adult Down Syndrome Centre in Park Ridge, Illinois, USA

ME8 NS HG22

Dr McGuire will further expand on the strengths and weaknesses of teens and adults with Down syndrome in this session.

Nutrition & Lifestyles

Food, Feeding, Family…Freedom: the Keys to Building Healthy Lives

Joan Guthrie Medlen, RD, LD, USA

ME9 BS Q121

Creating healthy lives for individuals with Down syndrome and their families requires a blend of science, education, creativity, and tenacity. This presentation touches on a bit of each illustrating the simple, yet complex task of promoting healthy eating and independence. The details of which will be shared in the afternoon "Meet the Expert" Session.

Ensuring Best Possible Hearing

Mr Patrick Sheehan MB BCh, M.Phil., FRCSI, FRCS(Ed), FRCS(ORL-HNS), UK

ME10 BS QG13

This will be your opportunity to meet Mr Sheehan in the 'Meet the expert' session where he will be happy to answer specific questions from parents.

Clear Speech & Language
Strengthening weaknesses? Weakening strengths?

Dr Clothra Ni Cholmain & Dr Aine Kelly, IRELAND

ME11 NS HG23

This session will open with a brief review of the trajectories of language change and of some of the constraints encountered by those with additional chromosome 21 material in following these pathways. It will provide a brief review of ways that developmental pathways or stabilized systems in language can be changed and will encourage participants to debate the costs and benefits of the focus on strengthening weaknesses common in 'expert' approaches.

It is hoped to have a panel of speech and language therapists who have experience of working on a range of aspects of the language system present to contribute to the presentation.

Ensuring Best Possible Vision

Margaret Woodhouse, Top Expert in Vision for people with Down Syndrome, UK

ME12 BS QG27

The most common questions about eyes and vision asked by parents are:

- 'How can my child's eyes be tested?'
- 'How can I persuade my child to wear his/her glasses?'
- 'How well does my child see?'

Maggie will prepare answers to these and other questions, and will respond directly to the audience in providing the information that they request.

Supporting Language & Communication

Jean A. Rondal, Emeritus Professor of Psycholinguistics, University of Liège, BELGIUM

ME13 NS HG20

This session will be for those interested in obtaining more detail on issues supporting Language & Communication and possibly some additional ones.

Sexuality

David Hingsburger M.Ed, CANADA

ME14 TH

Do you know the single most important social skill for the maintenance of human relationships? You will after this session.

Oral presentations

Chronic Constipation Due To Dolichosigmoid (Sigma Elongatum) In Children With Down Syndrome

Wolfgang Storm, St.Vincenz Hospital Paderborn, GERMANY

O61 MH

Chronic constipation is a frequent finding in patients with Down syndrome. It is very often layed aside as a functional disorder specific for people with Down syndrome without considering that there are organic causes which are not only treatable but even may be more frequent than in the general population.

To establish the incidence of dolichosigmoid in children with Down syndrome.

We surveyed 731 patients with Down syndrome of our Preventive Medicine Clinic.

Beside patients with Hirschsprung´s disease (18) we were able to make the diagnosis of dolichosigmoid (sigma elongatum) in three patients. This disease is considered a treatable congenital or acquired anomaly which can be detected by means of an enema of the colon (after excluding the diagnoses of Hirschsprung´s disease or other dysganglionoses, respectively).

It has to be emphasized that every case of chronic constipation has to lead to further diagnostic studies to prevent complications and to improve the quality of life of patients with Down syndrome.

The Role Of Chlorhexidine In The Management Of Periodontal Health In People With Down Syndrome

Nunn JH(1), Thomas W(1), Kelly A(2), Fitzpatrick L(1), Claffey N(1)
1. Dublin Dental School And Hospital, Trinity College Dublin, Ireland.
2. Small Area Health Research Unit, Department Of Public Health & Primary Care, Trinity College Dublin, Dublin Dental School & Hospital, IRELAND

O62 MH

Periodontal disease results in premature tooth loss in some people with Down syndrome.

This study aims to test the impact of the use of chlorhexidine products alongside regular professional cleaning, on periodontal health and patient quality of life.

After ethical approval, patients were recruited as an opportunistic sample from those already attending the Dublin Dental Hospital as well as through Down Syndrome Ireland. Oral and dental health was assessed at baseline and 3-6 monthly until Spring 2009, with the following indices: dental caries- dmft/DMF, Modified Gingival Index, Pocket probing depth, Gingival Bleeding Index, Calculus Index and the Plaque index. Quality of life was assessed using a tool modified by Allison et al. Patients attended 3- or 6-monthly for professional oral prophylaxis, supplemented by either 1% or 40% chlorhexidine varnish, in a double blind cross over design.

29 patients were recruited;3 were lost to follow-up. Data will be presented on the clinical outcomes as well as the quality of life assessment.

Based on the study outcomes, recommendations will be made for the optimal frequency of dental visits and the most appropriate adjuncts to supplement toothbrushing. This study was supported by a grant from the Oral and Dental Research Trust, London, UK.

The Metabolic Syndrome Characteristics In Down Syndrome

Ariel Tenenbaum, Yaarit Malcah, Ishaya Wexler, Rebecca Brooks, Floris Levy-Khademi, Hadassah University Medical Center, ISRAEL

063 MH

The metabolic syndrome (MES) and its characteristics - obesity, hypertension, dyslipidemia and insulin intolerance are major risk factors of developing cardiovascular diseases, diabetes and Alzheimer's disease. In the general young population its prevalence is 4-5%, and 49% in the severely obese. Dietary modifications with physical activity may lower the prevalence of MES. Down Syndrome (DS) is a possible risk factor for developing MES due to typical medical conditions, e.g. lower basal metabolic rate, hypothyroidism, obesity and insulin resistance.

To determine the prevalence of the MES Characteristics in children with DS visiting a referral center, and to identify possible subgroups with increased risk of developing MES.

99 children visiting the Down syndrome medical center at the Hadassah University medical center in Jerusalem were evaluated for weight, height and blood-pressure, and most of them for fasting glucose, lipids and physical activity as well. The control group included 31 obese patients from pediatric clinics. Overweight children with DS were compared with non-overweight children with DS and non-syndromatic overweight children.

57.6% of children with DS were obese, BMI 85%, 27% had severe obesity BMI 95%. The overall MES incidence was 8.3% in overweight children with DS compared with 14.3% in non-syndromatic overweight children.

There were no statistically significant differences in MES characteristics between overweight children with DS, non-overweight children with DS and overweight non-syndromatic children.

Testing for MES characteristics in children with DS leads to early diagnosis, followed by adequate treatment which may improve quality of life and longevity.

Congenital Heart Disease In Children With Down Syndrome

M.Kelmendi, R.Bejiqi, University Children's Hospital, ALBANIA

064 MH

Down syndrome (DS) is associated with a wide range of variable clinical features, with a congenital heart disease (CHD), as the most common one

1. To evaluate the frequency of CHD in children with DS in our country

2. To stress the problems regarding cardiosurgery, children with DS and CHD are faced with

Between 2000 and 2007, at University Children's Hospital in Prishtina 192 children with DS, aged from 1 mo to 16 years have been examined.

The diagnosis was performed using: clinical features and laboratory.

Of 192 children with Down syndrome, 98(50.4%) have simple or more complex congenital heart disease, while 93(49.6%) are CHD free.

The most common CHD was complete atrioventricular septal defect, ventricular septal defect, atrial septal defect, patent ductus arteriosus, pulmonary stenosis, hyperthrophic cardiomyopathy, exudative pericarditis. Like reports of many authors, aortic stenosis, coarctation of the aorta and complex CHD were not detected in children with DS.

After the diagnosis has been made, the indications for cardiosurgery have been made in about 47 children with CHD (48%). From this group of Children with DS, as " a less desirable" group, only few of them have been successfully operated, while most of them developed complications (pulmonary hypertension, heart failure) or died.

Since life expectancy in children with DS depends on heart condition, the early detection and surgery of CHD in such children is necessary.

So, we are advocating a world with equal rights and opportunities for people with DS, including the right for medical treatment and cardio-surgery too. Nobody won't forget "People with Down syndrome is people first at all".

Understanding The Impact Of Puberty And Menstruation On Females With Down Syndrome

Dr Margaret Kyrkou, Flinders University, AUSTRALIA

065 MH

When speaking to parents of females with developmental disability about the impact of premenstrual syndrome on their daughters, parents also reported their daughters not following the expected pattern from puberty through to menstruation.

The researcher further explored those parent perceptions encompassing females with a range of developmental disabilities, but this presentation focuses on the 28 females with Down syndrome.

Following ethics approvals, organisations forwarded a request form and reply paid envelope to potential respondents. Respondents agreeing to complete the questionnaire were then posted the questionnaire with another reply paid envelope.

43% had cyclical symptoms up to a year preceding menarche, 29% exhibited mood changes. A surprising 32% had unexpected physical symptoms of incontinence, vomiting or diarrhoea. Breast development was not the first signs of puberty in 52%, and 2 females reached menarche without any warning changes. First sign of puberty to menarche was under one year in 46%. 48% were reported to have dysmennorrhoea, and 75% reported to communicate well. 60% indicated pain when injured or unwell, but only 14% indicated premenstrual or menstrual pain. For the other 36%, pain was deduced from behavioural or physical changes. One mother was upset when she realised her daughter's screaming was due to her broken arm, yet her daughter usually communicated well.

Preparation of the girl for menstruation needs to begin early, and physical cyclical symptoms premenarche need to be medically recognised. Menstrual pain not being identified verbally, and apparently responding to paracetamol only, raises the concern of underdiagnosis and ineffectual management.

Effects Of Rapid Maxillary Expansion In Down Syndrome

Casimiro De Andrade, Miguel Palha, Viviana Macho, Monica Pinto, Carla Moura, Faculdade De Medicina Dentãria Da Universidade Do Porto, PORTUGAL

066 MH

In Down syndrome (DS), the respiratory dysfunction is among the pathologies that cause most worries and imply serious dysfunction in the individual development, learning ability and sleep capacity, as well as having large family repercussion.

This prospective randomized study assesses the effects of rapid maxillary expansion (RME) on otolaryngological disorders in children with Down syndrome.

This clinical trial assessed the effects of rapid maxillary expansion (RME) on ENT disorders in 24 children with DS aged 5 to 12 years, randomly allocated to receive RME either or not.

In the RME group, the yearly ENT infection rate was reduced when assessed after device removal (p,0.01). The parents of RME children reported a reduction in respiratory obstruction symptoms. Audiological assessment revealed improvements in the RME (p,0.01). Cephalometry showed increased maxillary width in the RME group.

RME resulted in a reduction in hearing loss, yearly rate of ENT infections and parentally assessed symptoms of upper airway obstruction, and an improved articulation, tongue mobility and intelligibility.

Cutting this cycle of mouth breathing and increasing the area for nasal ventilation can provide a solution for some breathing difficulties, a reduction of tongue protrusion and drooling, as well as the high incidence of repeating respiratory infections and the high rates of compression and crossbites.

These aspects often lead to an aesthetic improvement noted by the parents. By placing the tongue in its normal position, the speech is improved, and so the aesthetic and self-confidence of the individual, facilitating his integration in society.

The use of this device should be included in the suggestion to medical and connected Associations of parents of Down's Syndrome children.

My Story

Mr Sujeet Desai, USA

067 TH

Sujeet starts with his story showing a slide show on his power point musical presentation. At times he plays violin, clarinet & piano to express his thoughts and to send messages. Starting from his early child education, to preschool, elementary, middle and high school years, till his post secondary music academy study away from home for 2 years!

Then his living in a group setting home for a year before he got married to move in his own apartment with his wife. He talks about his support service plan "Self Determination and Consolidated Support Service" that is been helping make independent living possible. He talks about his hardship, his struggles, his frustrations and his and his parents advocating to finally bridge the gap of his disability and become a role model around the world.

He talks about how his mother believes his music and many other abilities have helped him to improvise his disability to be able to live a meaningful life. At time his mother Dr. Sindoor Desai joins him to talk about Howard Gardner's "Multiple intelligences" therapy and how Sujeet is a perfect example of it.

Who should attend this workshop: Self advocates: youth & young adults, their parents and families, service providers, educators especially school teachers, music therapist, Care takers or anyone who desires to advocate for individuals with special needs.

Down Syndrome And Automatic Processing Of Emotional Facial Information

Morales, Guadalupe & Lopez Ernesto Universidad Autonoma De Nuevo Leon, Psychology Department, Cognitive Science Laboratory, Universidad Autonoma De Nuevo Leon, MEXICO

068 TH

Research on mental retardation is a key component to understand the relation between cognitive and emotional development (Sroufe, 1998). One of the most relevant genetic conditions to explore this relation is the Down syndrome for several reasons. For example, persons with Down syndrome (DS) are characterized as highly emotional individuals (Smith & Walden, 1998). This behavior may be related to a dysfunctional neural architecture. However, the consequences of this dysfunctional neural on the cognitive emotional architecture remain at large unknown.

The goal was to look for deficits on automatic and non automatic evaluation mechanisms of emotional information on DS individuals.

Participants with Down syndrome (DS) and control subjects were tested in two affective priming studies. The first one required subjects to recognize emotional faces with a short SOA (300 ms). The second one included an indirect measure of affective priming associated with an attention task with a long SOA (2000 ms).

The principal result was the observation that participants with DS do not recognize negative information at short SOAs (automatic evaluations) and that these individuals report significant slower latencies than control subjects to facial recognition through all experimental conditions.

Implications of these results to appraisal theories of emotion as well as behavioural therapy are discussed.

Keywords: Down syndrome, cognition, emotion, affective priming, facial recognition.

Perceptions Of Parents And Speech And Language Therapists On Mainstream Primary Education

Siobhan Keohane, Ciara Skehan & Clare O'shaughnessy, Nui Galway, IRELAND

069 TH

Increasingly, children with Down Syndrome are receiving education in mainstream settings. A growing body of evidence and legislation supports inclusion of children with Down Syndrome in mainstream education. However, little research has investigated Speech and Language therapists' and parents' perspectives on school transition for children with Down syndrome. From an Irish perspective, very limited research documents experiences of inclusion therefore the proposed study is important.

This research study proposes to qualitatively investigate parents' and speech and language therapists' perceptions and experiences of inclusion in mainstream primary school.

Semi structured interviews will be carried out during January and February 2009 with five parents and five speech and language therapists. A detailed analysis of themes will be carried out. The NUI Galway Research Advisory Group has approved the study. Their thoughts and perspectives will be ascertained via interviews and detailed analysis will be completed.

On completion of this research, an understanding of the reasons parents opt for mainstream inclusion and their experience of inclusion should be apparent and an understanding of what factors contribute to the speech and language therapists decision making for a child and what impacts their recommendations to parents about mainstream school.

Parent Perspectives On The Application Of The Handwriting Without Tears® (HWT) Programme With Children With Down Syndrome In An Irish Context

Sandra Patton, Bsc. Cot & Dr. Siobhan Mac Cobb, Trinity College Dublin, Trinity College Dublin, IRELAND

070 TH

This paper will present the findings from the parent's perspectives on a large scale study that was conducted in three counties in the Republic of Ireland. The purpose of the study was to investigate the application of the HWTÂ® programme using a

collaborative approach which involved 50 children with Down Syndrome, their parents, teachers and an occupational therapist. This study was conducted over a ten month period in 2006/2007. The children ranged in age from five to ten years.

This presentation will report on the parent's perspectives on the application of the HWT® programme.

A mixed methods approach was used. This included pre and post intervention questionnaires with 50 parents, a post intervention focus group with six parents, field notes recorded during the intervention phase and cross case analysis using a case study design.

The results being presented will include parent perspectives on:

- Benefits of using the HWT® programme
- Limitations of using the HWT® programme
- Practical issues
- The collaborative approach used

Benefits were increased interest by the children in prewriting/ handwriting, user friendliness of the programme, and variety of materials included.

Limitations included time constraints, child being involved in other programmes, emphasis on capitals in the programme.

Practical issues such as level of child's health, tiredness and fluctuating mood influenced the ability to carry out the programme.

The collaborative approach was found to support parents in implementing the HWT® programme. Recommendations include need for ongoing occupational therapy support and guidance to implement the HWT® programme.

Special Education In Our Schools Through An Inclusive Lens

Dr. Ashleigh Molloy, Transformation Education Institute, CANADA

071 TH

Schools must view students through an inclusive lens that promotes different abilities holistically. Educators and parents will be introduced to a paradigm shift in thinking about students with Down syndrome. The presentation will outline them as differently-abled rather than disabled and having assets as opposed to deficits. Curriculum and support resources necessary for success will be referenced and essential strategies demonstrated that support the mission of socially just classrooms for all learners.

A qualitative research study involving educational stakeholders in several countries was utilized. Responses were compiled and summarized.

There is a uniform belief that inclusion is a social justice issue and as such should be practiced in all schools. If inclusion is to be successful, staff training, resource support and home-school collaboration are imperative.

Research based evidence on the benefits of inclusion were substantiated.

This supports the UN emphasis in their Education for All document that "All" includes both typically developing and differently-abled students learning together in an inclusive environment. Howard Gardner's Multiple Intelligence Theory and the work of Pierre Bourdieu need to be implemented within teacher education programs in order to affect systemic change in the way we educate students with Down syndrome.

To Go Boldly

Alex Snedden, Accomplished Public Speaker, Role Model & A Young Man With Down Syndrome. Lorna Sullivan, Chief Executive Of Standards Plus (Lorna Sullivan), NZ

072 BS QG15

The lives of people with disabilities continue to be defined by the diagnosis they hold and the assumptions about the cognitive and functional limitations that such a diagnosis might imply.

This presentation demonstrates how a commitment to Social inclusion and socially valued roles operate as a principle means of address to such devaluation.

This workshop will share some of what we have learned in our attempts to imagine better in the lives of disabled people and their families, demonstrated through the life experience of one young man with Down syndrome and his family.

It will look at how families and disabled people can themselves expand their circles of influence and relationships and key factors which need to be considered by provider agencies if they are to truly invest in building confidence and competence within community.

Our work has been informed by applied Social Role Valourisation; a commitment to social inclusion that develops people's potential and a genuine commitment to and understanding of what it means to work in partnership with young people and their families.

A young man who has taken the first steps towards his life of contribution and social value in community. A family who doesn't walk the journey alone and a community of support who act as the dream carriers for this life over the long term.

This presentation demonstrates through the story told by one young man of what can be possible when families are nurtured in the hopes and dreams they hold for their children. When support works in partnership with families and where supported informal networks take precedence over the paid and formal.

Quality Of Life And Quality Of Care Of People With Down Syndrome

Dzurova Dagmar, Association Of Parents & Friends Of Children With Down Syndrome, CZECH REPUBLIC

073 BS QG15

The Czech Republic is an example of a country where lives of people with disabilities were out of interest of the community for a long time period. Academic research in this field has been very limited.

This presentation investigates the quality of life (QoL) and the quality of care (QoC) in people with DS in regard to social policy developments.

As a part of the cross-cultural DIS-QOL project the QoL and the QoC was measured using the WHOQOL-BREF & Disability module and the QOCS instruments. Multivariate methods were used to analyze the data. A total of 283 respondents with disabilities (42 respondents with DS and 84 relatives and professionals - Proxy study) were included in the analysis. The QoL/QoC was examined in relation to demographic characteristics and both institutional and community models of care.

Instruments provided a suitable method of assessing the impact of concepts such as normalisation, self-determination, individualised support systems, and enhanced role status on the lives of people with DIS.

The study results correlated with the different types of support/service provision and with work participation. Typical examples of service practice in the Czech Republic are discussed.

Locked Away And Safe Or Living Large In Berkeley, CA

Kathryn Edwards & Megan Brown, Institute For Applied Behavior Analysis, USA

074 BS QG15

The Institute for Applied Behavior Analysis initiated a project focused on deinstitutionalization in lieu of incarceration, included in this project was a 27-year-old woman with Down syndrome. The presenting challenge was the woman's strong assertion that she could not survive without intensive medical treatment.

This individual case study will exemplify the alternative strategies which honor this individual and actualize her desire to reconnect with her family in a setting which instills safety rather than fear.

Recognizing her fear that medically trained staff would not readily be available in her own home, transitional activities focused on full participation in future medical treatment and staff training specific to medical needs.

Given the history of life-threatening actions to access emergency medical service an intensive behavioral treatment plan was required. Efforts to progress beyond dependency upon paid/professional supports, necessitated a systematic training specific to the personal development of the mind-body connection. Actualizing these strategies could only occur with the active participation of her family, friends, and professionals, her circle of support.

The harm she had experienced in prior failed placements, reinforced her insistence that only an institution had resources to meet her medical and behavioral needs but the innovative strategies utilized here allowed her the opportunity to successfully return to her home community and reconnect with family.

Years of institutional placement did not teach nor provide readiness for community living. Instead, this individualized approach to the service design has resulted in the first year of success in her own home.

Translating Quality Of Life Into Service Action: Use Of Personal Outcome Measures In Ireland

Dr. Bob Mc Cormack & Margaret Farrell, St Michael's House Services, IRELAND

075 BS QG15

The aim of this survey is to assess the current QOL of adults with Intellectual Disabilities (ID) across a range of 22 service providers in the Republic of Ireland, using the CQL's Personal Outcome Measures (POMs). The results will provide a baseline for

A random sample of 300 Irish adults with disabilities, who are supported by Irish disability providers, were selected for the survey, and interviewed using POMS.

Results: The participants in the survey had a mean of 9.4 out of 23 personal outcomes fully present at the time of the study. Individual scores varied greatly - 2 participants had no personal outcomes fully present, while one person had all 23 outcomes present. People living in campus settings scored lowest (average 7 outcomes), with those living at home had, on average, 10 personal outcomes fully present. Generally, the number of personal outcomes present varied with the severity of the disability, participants with a mild/moderate ID had on average 10 outcomes present, while those with a severe/profound ID had an average of 7 outcomes present.

Discussion: On average, participants had less than half their personal outcomes fully present at the time of the survey. This finding highlights the need to develop more integrated services, to maintain people in their local communities rather than remove them into special settings, and develop more reciprocal relationships with communities. The newer models of service such as individualised service design, supported employment and supported living, building social capital, offer this potential.

More Academics In Regular School?

Gert De Graaf (Department Of Orthopedagogics, University Of Gent, Dutch Down Syndrome Foundation), Geert Van Hove (Department Of Orthopedagogics, University Of Gent), Meindert Haveman (Department Of Rehabilitation Sciences, University Of Dortmund), Dutch Down Syndrome Foundation And University Of Gent (Belgium), NETHERLANDS

076 BS QG13

Studies from the UK have shown that children with Down syndrome acquire more academic skills in regular education.

Does this likewise hold true for the Dutch situation, even after the effect of selective placement has been taken into account?

In 2006 a first questionnaire was sent to 160 parents of (specially and regularly placed) children with Down syndrome (born 1993-2000) with a response of 75%. In 2007 the questionnaire was repeated. Questions were related to the child's school history, academic and non-academic skills, parental educational level, the extent to which parents worked on academics with their child at home and the amount of academic instructional time at school.

Academic skills in 2006 and 2007 were predicted with the other variables (2006) as independents.

1. Academics appear to be predicted reasonably well (Â±60%) on the basis of age, non-academic skills, parental educational level and the extent to which parents work at home on academics. However, more variance (Â±70%) can be predicted when the total amount of years that the child spent in regular education is added.

2. For the children in regular schools twice as much time was spent on academics.

3. Regularly placed children in 2006, but not so anymore in 2007, lost position in academics in comparison to children that were still regular in 2007, also after controlling for the other independents.

Regular children with Down syndrome learn more academics and this is not only due to selective placement.

Accommodations And Modifications For Including Students With Intellectual Disability Into The Mainstream Classroom

Mary Frances Edwards & Diane Lowry, Kerry Branch, Down Syndrome Ireland

077 BS QG13

Educators frequently struggle to truly include children with intellectual disabilities into the mainstream curriculum. Very often the child is sitting in the room, but doing work completely removed from the class discussion. In many cases, the school personnel are willing to include the child, but lack specific training and expertise in how to do so. Both teacher and parents could benefit from strategies for true inclusion.

We intend to provide a model for modifying classroom activities so that the child with an intellectual disability can feel (and be) a part of the interaction and learning occurring in the class.

This presentation will detail strategies that can be used by regular education teachers, special education teachers, and special needs assistants. The strategies will be very specific to encouraging participation in normal classroom activities. Techniques for adapting curriculum materials will be included. Ideas for modifying the learning environment to maximize participation will be emphasized.

Participants will be given a model of nine strategies for modifying and accommodating for special needs. Participants will have a deeper understanding of methods for adapting curriculum and activities to meet communication and learning needs of children with intellectual disabilities. They will also be stimulated to recognize true

inclusion and to further develop their own strategies and techniques.

This information will benefit personnel from mainstream schools, as well as parents with intellectual disabilities who are being educated in a mainstream school.

Mastering The Art Of Multi-Level Teaching ... The Key To Life Long Learning

Engelbrecht, A. & Swanepoel, H., Gauteng Department Of Education, SOUTH AFRICA & USA

078 BS QG13

In order to become a life-long learner, the learner with Down syndrome has to perceive learning at school level as truly meaningful - not necessarily on academic level, but especially at interpersonal levels. This can be achieved by learning together with the diversity within his own peer group, but at his own level of competence in different learning areas.

To be able to modify the content of a specific lesson, whilst working in the same context as the rest of the class.

An example lesson (Mathematics - from the planning phase through to the presenting and actual recording and reporting of outcomes to parents and other stakeholders) will be presented to attendees.

The emphasis will be on including the learner with intellectual impairment in a mainstream class of 35-40 learners with a wide range of learning needs.

The attendee will realize that:

- multi-level teaching practices do not only promote inclusion of learners with diverse learning needs, but even more importantly:
- it opens up endless opportunities for life-long learning as the learner now perceives learning not only as an academic endeavor (at a much lower level as his peers,) but as a socially uplifting activity.

ONE SIZE (a specific lesson) CAN FIT ALL....

you just need to be skilled - and willing - to alter the sizes

(plan, present, assess, record and report on different levels - but clinging to the same context)

Inclusion Vs Integration

Bryan Harman, Canadian Down Syndrome Society, CANADA

079 BS QG13

All children deserve to be welcomed in their neighbourhood schools. The United Nations stated in March 2007 that inclusive education was a right of all people. This is a shift in ideology from special education classrooms to educating all students within an inclusive classroom. As children with labels and disabilities enter the education system, the terms 'integrated' and 'included' are used to describe the classroom settings they will experience.

For all children to be able to exercise their right to an inclusive education, there must

difference is that integration models work under the premise that something is wrong with the child and needs to be fixed. Inclusion works under the premise that

Inclusion is an attitude, a value and belief system. All students are encouraged to belong, thus nurturing everyone's self esteem. In inclusion, students are 'participating' in school, as opposed to integration, where students are 'going' to school. Inclusion is really a function of relationships and attitudes.

Inclusion benefits everyone. Integration simply accommodates and benefits no one. Students with 'typical' abilities, teachers, students with 'different' abilities, parents

inclusive attitude.

Understanding that children are not broken, (integration), will allow inclusion to become a reality. Schools need to learn as well as teach and realize that successful inclusion will support all children reaching their potential.

Individualized Academic Intervention For Adults With Down Syndrome: Assessing Progress Over Time

Melissa L. Rowe, Ph.D. (Down Syndrome Of Louisville, Louisville KY), USA

080 BS QG13

Many young adults with DS experience a decline in academic skills after high school due to both a lack of post-secondary educational opportunities for adults with intellectual disabilities as well as decreased opportunities to utilize these skills in the real world. In hopes to reduce and/or prevent these declines, we designed a weekly academic intervention program for adults with DS. This presentation will discuss the program design, student goals and progress, and statistical findings.

To assess the change in adults with DS in both standardized scores and general level of academic performance over the course of a 5-year period while enrolled in our program.

A longitudinal study of 21 young adults with DS was conducted at Down Syndrome of Louisville's Adult Literacy Program. Standardized assessments of academic achievement as well as general cognitive ability (i.e., IQ) were obtained once per year over the course of three to five years (depending on the student's enrollment date).

Data analysed that compared students' pre-enrollment standardized achievement scores to those obtained three or more years later revealed a significant difference between the two time points ($p<.05$). In addition, all 21 students either remained the same or increased in score on both the achievement and IQ tests (i.e., no students regressed). Multiple other analyses were conducted and will be discussed.

These results indicate a great benefit to ongoing academic intervention for adults with DS. Not only did academic skill significantly increase in these individuals, but scores of general intellectual ability also increased.

'Before and After' with Violin Recital

Emmanuel Bishop, USA

081 BS QG27

"Before and After" shows the life of a 12-year-old self-advocate boy with Down syndrome: his interests and accomplishments in sports, music and academics. Golf, biking, violin, swimming, etc. video clips will be shown.

1. Highlight the abilities in Down syndrome. 2. Counteract the low expectations in Down syndrome. 3. Show that the joy of living does not preclude individuals with Down syndrome.

Pilot Study: 'A Friend In Need...' The Challenges Of Friendships For Adolescents And Young Adults With Intellectual Disability Who Live In Rural Tasmania

Zournazis, H., Harris, M., Dr. Orpin, P., (University Department Of Rural Health, Tasmania), University Department Of Rural Health, Tasmania, AUSTRALIA

082 BS QG27

Friendship formation is an essential element for well-being, especially in the

development of one's identity during adolescence. Adolescents/young adults with intellectual disability (ID) are faced with significant additional barriers in their formation and maintenance of friendships, particularly for those who live in rural environments where there are fewer choices and opportunities.

There is a growing amount of literature exploring the social networks and relationships of individuals with (ID) but little about the issues faced by those who live in rural environments.

The study explores this gap in the literature.

This study used an interpretative qualitative research approach. Seven face to face in-depth, semi-structured interviews were conducted with parents/ carers of adolescents/ young adults with mild, moderate and severe intellectual disability who live in rural Tasmania. This method was employed to provide a perspective not well covered in previous studies.

Parents/carers highlighted the limited services that reduced opportunities for formation and maintenance of friendships. Isolation and mobility issues in rural areas contributed to an increased need for parental involvement. Nevertheless, those parents/ carers who were themselves highly socially connected, stated their adolescent/ young adult with ID had extensive social networks and support. Most parents/ carers claimed the importance of friendships as they contributed to increased happiness and reduced loneliness.

Living in a rural environment compounds the many issues that individuals with ID face in the establishment and maintenance of friendships. This study provides a platform for a larger more representative study.

Fighting Isolation

Leonora Sh(1), Myrvete K(2), Shqipe S(3), (1) Parent Support Group Of Down Syndrome Association Of Republic Of Kosova (Western Balkan) (Ngo Dsk), (2) Pediatric Clinic, University Centre Of Clinics Kosova. (3) Down Syndrome Resource Center Prishtina, Ngo Dsk, Down Syndrome Association Of Kosova, ALBANIA

083 BS QG27

Parents of the children with Down Syndrome (DS) in Kosovo, as result of lack of information find themselves in situation without any hope or alternatives. Lack of information in general on how the individuals with DS should be treated has led the community of 516 members (regarding NGO DSK data base) in complete isolation, without hope or alternatives.

Persons with DS in Kosovo are isolated a part of society which is not presently being serviced by any relevant institutions or NGO's. Inclusion of individuals with Down Syndrome into the community is a meaningful contribution for everybody.

Since established of association (4th march 2007), several activities were taken place from parents, professionals and strong-minded people by increase the mobilization of community with DS, increase the level of interest of educational authorities and increasing awareness to society.

Four children with DS were register into regular primary school; nine to public kindergarten, fifty-two new parents of infants with DS were equipped with information from experienced mother in first weeks. Two programme were designed, the early education programme and Programme X 21. From first programme are benefiting 76 children under age 9 through three resources centers of NGO DSK.

The programme, X 21, consisted of three components, as follows: Training for the coffee preparer and waiter, decorative workshop and premises where the parents, professionals, students and interested media can meet and communicate. Presently, the programme is fully staffed with four youngsters/adults with Down syndrome aged from 19 to 24 years old.

By 'fighting the isolation', wrong stereotypes and an old fashioned mentality are commonly expressed concerning DS in Kosovo. The establishment of a place/premise where interested guests would be served and discuss with the DS persons themselves will work to eliminate these old notions about DS in Kosovo.

"Stepping In Cinderella's Shoes ": A Young Girl's Quest For Identity And Empowerment

Esther Joosa, National Institute Of Education, SINGAPORE

084 BS QG27

In make belief play young children assume roles. In this way they tell others who they are and what they want to be. The process of role-taking is important in the formation of identity and a key means to empowerment. While there is an increased focus on understanding the role of dramatic play in the development of agency and identity in early childhood, there is little awareness of similar processes with young individuals with Down syndrome.

Set against a backdrop of the author's art program, this presentation provides an insight in the world of an eight-year old young girl with Down syndrome, her make-belief play and interactions with author. It aims to highlight the possibilities of dramatic play in social and emotional development.

Based on socio-cultural perspectives, this qualitative investigation makes use of a critical cultural discourse analysis framework in order to examine and analyze the participant's quest for on power roles.

The findings show an intricate interplay of participant and author on issues of agency and identity. It shows the ability of the participant to take on different roles and to understand the social rules related to these roles. It further brings forward the importance of responses.

The investigation draws attention to several intertwined issues, the need to understand the power of dramatic play, the nature of the meaning making process as well as the importance to include young children with Down syndrome in discussions on concepts such as agency and identity.

"The Rarely Heard Voice": Students With Moderate General Learning Disabilities Share Their Experiences Of Friendship In Mainstream Schools

Dr Michael O'Keeffe, Department Of Special Education, IRELAND

085 BS QG27

This presentation will focus on how students with a Moderate General Learning Disability experience friendship in mainstream schools. Having close friends is a fundamental need for most people. It is satisfying to have close friendships with others as they serve to enrich one's life. Many writers would even claim that friendships are in fact, the single most important factor influencing a person's quality of life.

Using a compendium of innovative methods six students, including five with Down syndrome, in five different mainstream schools share their experiences of friendship. These are outlined in this presentation and the 'voice' of the student is privileged at all times.

Consideration is also given to the steps that schools take that promote or inhibit the formation of friendships between this group of students and their mainstream peers.

A Multicenter Vitamin E Trial In Aging Persons With Down Syndrome: Progress Report

AJ Dalton, PS Aisen, HF Andrews, MC Sano, W-Y Tsai, & Members Of The International Down Syndrome Alzheimer Disease Consortium, New York State Institute For Basic Research In Developmental Disabilities, USA

086 BS Q121

Persons with Alzheimer disease from the general population have been shown to benefit from a two-year regimen of vitamin E, 2000 units daily. It is not known whether or not a similar regimen will have the same effects in aging persons with Down syndrome.

To evaluate the safety and efficacy of vitamin E (1,000 IU) administered twice daily for three years to slow the rate of cognitive/functional decline in 350 persons with Down syndrome 50 years and older, with or without a diagnosis of Alzheimer disease.

Method: Randomized, double blind, placebo-controlled, parallel group design with stratification by geographic site and presence of Alzheimer disease according to DSM-IV criteria. Primary analysis will follow the intent-to-treat principle, including all research participants who complete the randomization and baseline visit. Tests of statistical significance are set for the two-tailed and .05 alpha levels for the primary and secondary outcome measures. The Brief Praxis Test scores (primary outcome measure) at 7 time points will be analyzed using the Generalized Estimating Equation (GEE) method.

The cohort consists of 205 men and 137 women. Mean age is 54.4 yrs. (sd=4.31, range=49-71 yrs) with DSM IV mental retardation levels of mild (21.7%), moderate (53.0%), severe (19.4%), and profound (5.9%). Dementia status: No Dementia (72.7%), with Dementia (27.3%). Six-monthly visits are still underway for some participants. Following trial mid-point, a scheduled interim analysis of unblinded data was conducted. the Data and Safety Monitoring Board recommended that the trial continue to completion. Completion is expected in 2010.

Conclusion: A positive finding of a benefit of vitamin E could have significant impact on the care practices for persons with Down syndrome functioning at all levels of intellectual disabilities who are at risk for Alzheimer disease.

Relationship Between Amyloid β (Aβ) Protein And Immune Inflammatory Markers In Down Syndrome

P.D. Mehta, B.A. Patrick, S.P. Mehta, M. Barshatzky & A.J. Dalton, Institute For Basic Research, USA

087 BS Q121

Brain autopsy data from DS persons showed that the neuropathology of Alzheimer disease is always present in DS forty years of age and older. The core protein of the neuritic plaques is amyloid ß (Aß) protein. Studies have supported the role for immune abnormalities and inflammation in DS. Levels of proinflammatory cytokine (e.g. IL-6), and immune activation marker (e.g. neopterin) are increased in DS plasma than controls.

We hypothesized that levels of proinflammatory cytokine, tumor necrosis α (TNF α), and inflammatory marker Cystatin C would be higher in DS than controls, and would correlate with Aß levels.

The study included 40 DS (mean age 44 (30-62) years), and age-matched controls. Plasma levels of two isoforms of Aß protein namely, Aß40 and Aß42, TNFα, and Cystatin C were quantitated using an ELISA.

Aß40 and Aß42 levels were higher in DS than controls (P<.001), and TNFα and Cystatin C levels were also higher in DS than controls (P<.001). Although there was significant correlation between Aß40 and Aß42 level (r=.6, p<.01), there was no relation between TNFα or Cystatin C with Aß40 or Aß42 levels.

The data suggest that an extra copy of the gene for amyloid precursor protein leads to increases of both Aß40 and Aß42 in DS. The higher TNFα and Cystatin C levels in DS indicate a chronic state of immune activation in DS. Because there was no relation between Aß with TNFα or Cystatin C, increases in inflammatory markers reflect more infections than AD neuropathology in DS.

Cost And Quality Of Life In Service Delivery For Persons With The Dual Disability Of Down Syndrome (DS) Alzheimer's Dementia (AD)

McCarron, M., Trinity College Dublin & McCallion, P., University At Albany USA. School Of Nursing & Midwifery, IRELAND

088 BS Q121

Providers have responded to AD among persons with DS by supporting ageing in place, creating specialized units or encouraging transfer to more restrictive settings with greater medical supports (Janicki et al, 2000) However the question remains as to what specific care settings may be most useful in addressing and responding to dementia care needs of this increasingly at risk population in terms of both cost effectiveness and quality of life outcomes.

Determine which of three types of settings most cost effectively offer acceptable Quality of Life for persons with DS and AD.

Carers completed instruments on 92 persons with DS and AD drawn from 22 providers and served in community group homes, specialized dementia units or institutional and campus based settings. A three factor Quality of Life measure consisted of measures of confirmed dementia, functional, health and psychosocial status, and leisure participation (Factor 1), perceived difficulty in care (Factor 2) and the home environment (Factor 3). Cost of care was also calculated. Cost and quality of life findings were then compared by type of setting.

Quality of life was found to be higher in community and specialist dementia settings. Significant quality of life differences were found in the home environment and perceived quality of life factors. Costs were lower in institutional settings and comparable for community and specialist dementia settings.

Historical concerns with more institutional settings remained, community settings were more challenged by changing staffing needs and specialist settings offered quality care but not dramatic improvements over those found for ageing in place.

Understanding The Onset Of Dementia Symptoms

McCarron, M., Trinity College Dublin; McCallion, P., University At Albany USA; Mulryan, N., Lane, J., & McLaughlin, M., Daughters Of Charity Service, School Of Nursing & Midwifery, IRELAND

089 BS Q121

The realization of ageing years has been an incredible success, however, older persons with Down syndrome are uniquely at risk of developing Alzheimer's disease (AD) and account for about one third of all people with intellectual disability who have dementia. The prevalence of dementia in persons with DS exceeds that of the generic population and is estimated at 15 to 45% of persons with DS over 40 years of age.

To understand the patterns and predictors of onset of dementia symptoms by longitudinally following a sample of 80 women with Down syndrome.

After baseline collection of genetic data, a comprehensive dementia assessment using ICD criteria included administration of the Test for Severe Impairment (TSI) the Daily Living Skills Questionnaire (DLSQ), Down Syndrome Mental Status Examination

(DSMSE) and measures of co-morbidity. Periodic reassessments over 12 years tracked the onset and course of dementia symptoms in a sample of 80 women with DS aged 35 and over.

At baseline year (1996), seven cases were diagnosed with dementia, according to modified ICD-10 criteria, giving a prevalence of 8.7%. Over the following ten-year period the prevalence of dementia increased dramatically, with a total of 62 people (78.5%) meeting the criteria for dementia by the 10th year. Rates of decline over time were also calculated and the value of the TSI instrument, in particular, ascertained.

Despite continued efforts in the development and validation of both informant based (carer-rated) and objective test instruments (client-rated), as yet there is no agreed consensus on the optimal battery of test instruments to be used in detecting and diagnosing dementia in persons with Down syndrome. Diagnosis is a process of recognising change from the person's previous level of functioning and then assessing that decline using available tools. Findings here advance our understanding and the potential to validate needed tools.

Maintaining Health And Independence In Older Years

McCallion, P., University At Albany USA; McCarron, M., Trinity College Dublin, IRELAND. Center For Excellence In Aging Services, USA

090 BS Q121

Many more persons with Down syndrome are enjoying ageing years and in turn many family caregivers find themselves continuing to care into advanced old age. They are families that increasingly care for each other, and maintaining good health and managing the symptoms of illness are increasingly critical to continued independence

To describe and recommend evidence based health promotion strategies for persons with Down syndrome and their caregivers as they age

Review the components and evidence for cognitive training, chronic disease self management, modified exercise and healthy eating programs including information on available resources.

Data will be provided on the programs that have been demonstrated to work for persons with Down syndrome and for family caregivers

It is important that we not lose the gains we have made for people with Down syndrome when they age and that we support their family caregivers. Practical evidence based health promotion strategies will be presented that can make a low cost difference today.

Life Events, Relocation And End Of Life Issues In Aging Adults With And Without Down Syndrome

Paul J. Patti, New York State Institute For Basic Research In Developmental Disabilities, USA

091 BS Q121

Adults with Down syndrome (DS) experience more age-related life events which have consequences on their quality of life, socialization and the provision of care.

The findings from two retrospective studies on life events exposure in aging adults with and without DS will be presented.

The first study looked at the types of life events that occurred over a 5 year period in 211 adults with and without DS above age 50. A second study analyzed the number of relocations that occurred over a 5 and 10 year period in 140 adults with and without DS who were born prior to the year 1946.

Relocations and medical events were found to be significantly greater in those with DS, whereas those without DS experienced a significantly lower number of all life events categories studied. In the second study, relocations to different settings were significantly greater in the DS group compared to the non-DS group. Placement in a nursing home for end of life care was significantly higher in the DS group due to the higher incidence of dementia.

From the categories of life events, changes in environment, experienced losses or separations, and medical events were a more common occurrence in the lives of adults with DS. The findings in the second study suggested that aging adults with DS encounter more relocations over time and are more likely to have their final placement in a nursing home than adults without DS of the same or older ages.

Reach For Your Dreams And Celebrate Abilities: Self-Employment Works For Me!

Dylan Kuehl, DK Arts: Visual & Performing Arts Co, USA

092 BS Q121

International winning artist and poet, Dylan Kuehl proves through his large life that Down syndrome is not the obstacle it is often perceived to be. His presentation is informational and inspirational. Hearts and eyes are widened to the possibilities of what can be accomplished if we say YES to our dreams.

Dylan utilizes his skills and abilities and is self-employed as a visual and performing artist and the owner of his own company, DK Arts.

Be witness to what can be accomplished when work is created that FITS the person, rather having the PERSON fit the work.

Educate and inspire self-advocates, job coaches, administrators and all that support individuals with disabilities to consider self-employment as an option. Customized employment is the goal and the desired outcome for everyone.

Dylan speaks and shows a PowerPoint that include movie clips, radio interviews, images of Dylan's art and poetry and ends with a 02:36 profile of Dylan's business featured on the PBS television show titled, Biz Kid$ and also his appearance on the new movie: Arts: Disabilities, Possiblilities and the Arts.

Participants will be motivated and inspired to help others build a strong support team, customize their employment and "Reach for their Dreams".

Profit is not always evident in the final numbers, but can be seen on Dylan's face when he stands up in front of an audience and begins talking. He is proud of himself and his accomplishments and wants to be an example for others to stand up and be heard when they request customized employment.

Fostering Personal Autonomy And Full Self-Awareness

Contardi A., Associazione Italiana Persone Down, www.aipd.it, Associazione Italiana Persone Down, ITALY

093 BS Q121

A child with Down Syndrome meets on the way towards the acquisition of autonomy two kinds of obstacles: on one end the difficulties due to his deficit, on the other the attitudes of fear and ambivalence of the environment, All that hinders the acquisition of personal autonomy, which is nevertheless achievable in spite of the presence of impairments.

Acquisition of a good level of autonomy is an essential condition for social and work inclusion and the attainment of a good quality of life in the adult age.

In Italy the AIPD has developed over the last 20 years pathways of education to autonomy for young and adult people with Down Syndrome. This work aims at achieving the relevant abilities and at the same time enhancing of an increasing self-esteem and self-confidence.

Since the first experience in 1989 different pathways have been activated in approximately 40 different local communities, with a total of 776 people with DS involved in 2008.

The young people with DS meet in small groups during their free time with the assistance of educational operators.

The methodology employed is based on training in practical situations and on the active involvement of the pupils themselves. The goals of the courses is the acquisition of strategic capabilities to tackle common problems of everyday life and promote self-esteem and self-confidence in younger and adult people with DS.

Acquisition of mobility training: autonomy in the use of public transportation even in complexes routes : with at least 80% of success rate.

Use of money in shopping;

Acquisition of capabilities to ask for help.

Increase in communication skills.

People with DS can achieve satisfactory levels of social autonomy, even in presence of mediocre teaching skills. An extra-school educational training aiming to cope practical problems, proved to be particularly effective even in promoting the desire of independence and self-assertiveness

Towards Full Social Participation

A Group Of 4 DS Adults & C.Dupas As Facilitator, Trisomie 21 FRANCE

094 BS Q121

Social inclusion can only be achieved through housing autonomy and work inclusion.

Trisomie 21 France has created two types of innovative and highly individualized services: the SAVS (Services d'Accompagnement à la Vie Sociale) and the Open SATs (Service d'Aide par le Travail Hors Murs).

The SAVS provide DS people with support towards independent living. They offer flexible, progressive and individual access to housing autonomy through three stages, each of them being independent and optional:

- various workshops within a training platform (budget, dietetics, housekeeping, sleeping outside home...)
- experimenting personal autonomy on a temporary basis in an ordinary environment, supported by the regular visits of a team of professionals but without any permanent presence of educational staff.
- living in their own flat on a permanent basis, receiving the same support as in the previous stage. These personal flats are found according to a series of criteria: work proximity, leisure activities, family and friends...

The Open SATs send DS people, protected by the status of 'handicapped workers', on secondments in ordinary firms. The ultimate aim being, in the long run, for these people to be directly engaged by the firms under a common law contract.

These services can be considered as bridges towards the full social participation of DS people. An ever-increasing number of people benefit from such devices and can now live in keeping with their personal project and in harmony with their previous experience of school inclusion and vocational training.

"Young And Enthusiastic", ICT-Based IADL Training

Gro Marit Roedevand, Riitta Hellman, Karde As, NORWAY

095 BS Q121

To a much greater extent than others, youths with mental disabilities need to train skills in ADL (Activities of Daily Living). The content and responsibility for such training is, however, not clear. Our basic assumption is that many youths with mental disabilities can benefit from earlier and more IADL-learning and -training (Instrumental ADL).

In our project "Young and enthusiastic", we wanted to find out for which areas of IADL there is a need for ICT-based learning programmes, and which of these programmes are feasible to realize on common technology platforms (such as PC and/or mobile phones).

Requirements specifications for IADL-learning were acquired from literature, informant interviews and the expert group of the project. A national survey of available programmes in the areas of IADL was conducted. A web-based study was conducted to pinpoint the most important challenges for IADL learning and -training.

In Norway, there are few ICT-based training programmes addressing IADL. Available programmes typically support training in ordinary school subjects, clock etc., and the content is often at children's or beginner's level. Youths can often manage to use ICT-based tools, and the level of content has to be adjusted to meet their level of language, skills and needs.

More structured IADL-learning and training will benefit many youths with mental disabilities. They are highly motivated to use PCs and mobile phones. Thus, development of age- and capability-adjusted programmes for IADL-learning and training on these platforms is strongly recommended.

Down who? The Image Of People With DS In Italy

Contardi A., Associazione Italiana Persone Down, ITALY

096 BS QG21

In the last 20 years the image of people with DS has been modified very much in Italy, thanks to the school and all levels integration, but also thanks to the activities of all the associations.

To show how a person with DS is seen today and the most important causes of this change.

Analysis of medias and public opinion 'reaction' through DS people visibility in the last years in TV and cinema.

Introduction of specific communication actions (poster, campaigns, movies,) and fund raising events organized by the Italian associations.

Interviews to unpractised people .

From the right to exist to the achievement of a social role

- Bigger presence, bigger recognizability but with the risk of new stereotypes
- Between realism and optimism to look at the past with thankfulgiveness, to look at the future with confidence
- The importance to listen to the protagonists
- Sharing experiences and look-out points

The importance of the experience of inclusion as a powerful factor of relationships and imagery transformation.

Usefulness to increase the communication channels.

The Use Of Lamh And Children With Down Syndrome: Parents' Views

Clare Salley And Clare O'Shaughnessy, Enable Ireland, IRELAND

097 BS Q122

Lamh is a sign system used to augment verbal communication and is commonly used with children with Down syndrome in Ireland. There is a body of evidence supporting the use of aided communication systems and it has been found that they facilitate early language skills in children with Down Syndrome.

This study aimed to explore and describe parents' experiences of using Lamh with their children with Down syndrome and find information on the benefits and challenges of Lamh use.

This was a qualitative study focussing on the lived experiences of the participants. Five parents of children with Down syndrome aged up to six years participated. The study was approved by NUI galway, Research advisory group.

The results were analysed using a framework approach. Five main themes emerged, which included; experiences of Lamh at the beginning; learning and using Lamh signs; benefits of Lamh; disadvantages of Lamh; improvements to Lamh. The results provided deep insight of parents' use of Lamh with their children. Both negative and positive aspects were discussed and improvements were identified. Four of the five parents reported that they would suggest the use of Lamh to another parent of a child who had communication difficulties.

The study revealed that parents' experiences of Lamh were positive and that they appreciated the benefits it provided to their children. The results provide evidence to support the use of Lamh and will help parents to make an informed decision when considering the use of Lamh.

The Links Between Signing And Talking

Sue Buckley, Gillian Bird, Julie Hughes, Rebecca Baxter, Stephanie Bennett, Angela Byrne, Michele Pettinato. Down Syndrome Education International, Portsmouth, UK

098 BS Q122

In most services, parents are encouraged to sign to support their children's communication development yet we know very little about the effects of signing on overall communicative development. In particular, we do not know how signs support learning to talk.

The aim of this study is to collect data on 1. use of signs to communicate over a 12 month period from at 18-42 months. 2. comprehension and use of spoken words over the same time period. 3. transfer from signing to talking. 4. variability in the communication patterns of this group of children in relation to cognitive skills, hearing status and speech production skills.

Records of the progress of 40 children, aged between 18 and 42 months at the start of the study, have been collected over 12 months. Using vocabulary checklists, all words understood, signed and/or spoken have been recorded. Their speech sound discrimination and production skills have been assessed. Each child has been assessed twice on the Bayley III at a 12 month interval and hearing records collected.

The results will be analysed to explore the questions set out in the aims, following completion of the second round of standardised assessments in May 2009.

The results will be discussed in terms of what we understand to be influencing individual progress in spoken language and sign use. The overall aim of this work is to be able to inform parents, speech and language therapists and carers on the most effective strategies to use for individual children.

Adults Living Adult Lives

Professor Roy Brown, CANADA / AUSTRALIA

099 BS Q122

This workshop deals with challenges and practical solutions in employment, community living, learning, and behavioural aspects of life for adults with Down syndrome. Based on the book series edited by the presenter and published by Down Syndrome Education International, the workshop covers many aspects of community life and its challenges as well as family quality of life issues that are faced by parents and siblings. The workshop is in lecture-discussion format so parents and support personnel can interact with the presenter on these issues.

Mr. and Son

Thomas And Bryan Lambke, Tempe Union High School District, UK

0100 BS QG22

My presentation includes introducing our son, Bryan, who is 26 and has been quite successful with his life after high school. He has held two jobs and is very active in Special Olympics and Best Buddies.

We intend to show people how someone with Down syndrome can be a success, regardless of the limitations society has imposed on him. We also discuss IEPs (Individualized Education Plan), which the schools use as a tool to place your child in classes, guardianships and our books.

I can talk for up to two hours but have no problem adjusting for time constraints. Bryan is great with a question and answer session. We also use a dozen poster boards that hold the numerous articles that Bryan and I have been featured in various magazines and newspapers.

We explain what Bryan has done since high school and what he does on a daily basis. We also explain how he has changed everyone in our family, not just us and his sister, and everyone that he meets.

My wife and I really were not sure how to raise Bryan when he was born in 1981, so we simply treated him as if he was "normal". We never forgot that he had Down syndrome but we knew if we taught him the same basic skills that we would to a baby without Down syndrome, We figured he would be ok. And he certainly is!

Dads Appreciating Down Syndrome

Simpson, S. & Meares, J., USA

0101 BS QG22

We have a remarkable story to share with fathers, grandfathers, uncles, and significant contributors to the lives of individuals with Down syndrome. That story is about Dads Appreciating Down Syndrome (DADS). The mission of DADS is "Assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome". This is our eighth year in existence and our seventh year presenting at an annual Down syndrome conference. DADS started with a few guys in Indianapolis, Indiana meeting for fellowship. We intended to create methods to impact the lives of families and individuals with Down syndrome. We wanted to contribute. The response to our first presentation at the NDSS Conference in 2002 surprised us. We thought we were presenting an overview of organization structure and activities with which we were involved. After the presentation people asking how they could start a local organization proved we found a need waiting to be met. The size of our audiences over the years has validated the thirst within our Ds community for opportunities for men to contribute. In Indiana we have about 100 men on the email group. There are quite a few men who can not come to meetings due to schedule conflicts but are active contributors to our social and fund raising

activities. There are 26 groups in the USA, UK and Australia. We provide an overview of our organization then hold a meeting. Our workshop presentation gives "DADS" an opportunity to take part in their first DADS Meeting.

Dads Appreciating Disabilities International

Graham Mayer, Dads Appreciating Disabilities International, AUSTRALIA

O102 BS QG22

Dads Appreciating Disabilities International is a peak body that encompasses all groups that support men who are touched by disability around the world.

Dads Appreciating Disabilities International aims to connect groups around the world to share information, support each other, problem solve and to create a worldwide network of friends.

Using web based technology; men are linked together via the web page, blogs, and email in real time. There will be a regular e-newsletter to share information and celebrations from around the world to ensure the groups are connected with each other.

Dads Appreciating Disabilities International has proven to be a prominent leader in keeping men together, stronger and a voice in their countries. There are leaders in Dads Appreciating Disabilities International in Australia, New Zealand, United States of America, Pakistan and interest in Ireland.

Dads Appreciating Disabilities International is for men around the world who have an interest in disability. Together around the world we can be a stronger advocate for the rights of people with a disability and stronger in supporting each other.

Dads Only

Graham Mayer & Ray Murray, AUSTRALIA / NZ & IRELAND

O103 BS QG22

'Dads Only' is designed to facilitate discussion between fathers of children with Down Syndrome. Issues and topics will be guided by the needs of the participants, to allow for dialogue between fathers, to give encouragement to each other and to share experiences, successes, failures and strategies. The session will be facilitated by Graham Mayer, father of an adult with Down syndrome and Mr Raymond Murray, Disability Consultant, New Zealand, UK and Ireland

Maths And Me! Learning About Mathematical Development By Listening To Young Children With Down Syndrome

Faragher, R.M. (Australian Catholic University); Clarke, B.A. (Monash University), Australian Catholic University, AUSTRALIA

O104 NS HG20

Being able to use mathematics effectively in the contexts of a person's life (numeracy) is an important aspect of quality of life. This is especially true for people with Down syndrome. In this presentation we will report implications from a study into the mathematical development of young children with Down syndrome undertaken in metropolitan and rural settings in Australia.

In our study, we aimed to understand the mathematical development of young children with Down syndrome. This has the potential to provide guidance to parents and teachers as they work with children to lay the foundations of lifelong numeracy development.

Our study interviewed a small group of primary school children with DS twice in a year. The interviews used a well established task-based semi-structured interview protocol where children were asked to perform mathematics tasks, often with the aid of equipment. We videotaped the interaction with the children and analysed their responses.

Analysis of our data indicates some important themes, some related to behaviour and others to mathematics. In this presentation, we will discuss key findings, including:

- Power of symbols in developing concepts of number
- Importance of language
- Distinguishing 'can't do' from 'won't do'

Our research has implications for curriculum development, intervention and support. In curriculum development, this includes determination of the 'big ideas' of mathematics learning for primary children with DS. Intervention possibilities to support the development of these 'big ideas' can then be identified. We will discuss these in this presentation.

Maths Is Easy

Mag. Bernadette Wieser, Institut Leben Lachen Lernen (Live Laugh Learn), AUSTRIA

O105 NS HG20

The first school- day is not the 'zero hour' for our abilities in calculating.

The mathematical development starts early in the childhood by developing basic abilities, which are especially represented by the conception of space and the visual and acoustic differentiation.

Strengthening these key competences means to stimulate mathematical development.

Most important aim of the lecture / workshop is to show that most people with Down Syndrome are able to manage the fundamental operations of arithmetic in using their own two hands. A well contrived concept enables them to add and subtract from 1 to 100. The fingers represent the column of units, the knuckles represent the column of tens. They can calculate wherever they are (for example in shops and restaurants)- without using any materials except their own hands.

Content of the lecture:

- Basic skills for mathematical development
- Prenumerical exercises
- Comprehension of the unit of quantity
- Fundamental operations of arithmetic from 1 to 100
- A video in English language shows 9 children with Down syndrome while they are counting and reckoning with their own hands

A new concept (developed in Austria) brings new chances for lifelong learning. Hundreds of children, teenagers and adults with Down Syndrome have a lot of fun with Maths and calculate successfully in their daily life.

Please feel free to order the video called "Maths is easy".

Speaker: Mag. Bernadette Wieser (39) mother of two children (Nicola, 14, was born with Down Syndrome); director of the Austrian Down-Syndrome centre Leben Lachen Lernen (Live Laugh Learn)/ educational work with children, teenagers and adults with Down Syndrome; teacher for handicapped children; teacher for early-intervention-educationalists.

Maths And Money

Squire A., Phillips J., Down Syndrome Society Of South Australia Inc., AUSTRALIA

0106 NS HG20

The Maths & Money Resource Kit has been designed to assist educators, carers, para-professionals etc, provide an individualised program that will maximise the student/adult with Down syndrome/intellectual disability ability to acquire the numeracy and money skills needed to foster independence and dignity in managing many aspects of everyday life.

The mathematic skills essential for the development of these life skills have been identified and sequenced in the form of a continuum. The continuum has been developed as a guide to assist teachers to identify these skills and plan a sequential program. This continuum should form the core of the student's mathematics program throughout their schooling.

Skills in the Number area have been linked to the development of skills in money, time and measurement eg the number line 0-12 relates to the introduction of the analogue clock as does counting to 5's to 60. Counting numbers 0-31 relates directly to the introduction of the calendar.

A sequence of skills in the strands of Space, Number and Measurement have been divided into seven levels, each level recorded vertically. It is intended that the skills within a level will generally be taught concurrently. The skills in each level rely on the mastery of skills listed in the preceding levels eg ordering numerals to 60, precedes counting by 5's to 60.

The Kit accommodates the specific learning styles of individuals with Down syndrome and intellectual disability and provides a comprehensive user's manual, worksheets and an extensive range of practical games and activities.

Number Skills Intervention Program

Teresa Condeço Psym, Luísa Cotrim Psym, Miguel Palha Md, Portuguese Down Syndrome Association/Child Developmental Centre Differences, PORTUGAL

0107 NS HG20

The Number Skills Intervention Program main purpose is to support those who occupy themselves with children with the Down syndrome, in order to promote number skills in family and educational environment.

In our presentation, we propose to highlight the main features of the "Number Skills Intervention Program", its methodology and strategies and the software and worksheets developed to facilitate children performance.

The program we are introducing was outlined for children and youngsters who learn through manipulating activities with concrete objects, instructions and visual strategies and the link between their knowledge and their daily competences. An educational software "Mimocas Numbers", was also developed as well as a set of worksheets as strategies to promote the acquisition and the consolidation of learning.

This Program is a great help to parents, teachers and therapists when outlining the individual educational program. Essentially, the program proposes a number of general and specific objectives that are supposed to be a support for the structured and systematic work of intervention in number competences.

These are some of the teaching strategies we suggest and that have proved to be effective in the procedures of teaching/learning:

- Emphasize the visual learning - ex.: photographs, pictures, drawings,
- Choose preferably hands-on activities and educational software.
- Offer worksheets with reduced number of items, with pictures, and provide several means of response.
- Make use of the computer and mainly educational software as a strategy that favours/privileges the visual processing, the concentration, the motivation and the autonomy.

Learning Mathematics In Mainstream Secondary Schools: the Experiences Of Francesca And Martina, Two Students With Down Syndrome

Monari Martinez E. & Benedetti N., Istituto Prof, Department Of Pure & Applied Mathematics, University Of Padua, Padova, ITALY

0108 NS HG20

The key questions are: Is it true that persons with Down syndrome are hopeless at mathematics? Might it be possible that their difficulties are mainly restricted to some fields, such as numeracy and mental computation, but do not encompass the entire domain of mathematics? What can we say about the mathematical topics that emphasise logic over few numerical abilities? Is the use of a calculator recommended? Our experience is that these students can solve mathematical problems, though they may have very poor numeracy skills – in fact, a familiarity with algebraic computation and analytic geometry can help to raise their self esteem and improve their numeracy too. Perhaps surprisingly, these students can learn and apply mathematical procedures such as those used to work with fractions, to solve equations, to solve problems with equations, to use equation formulas in a variety of other different contexts, and to work with Cartesian coordinates and formulas in analytic geometry. One example is a problem in analytic geometry, in which students must connect points on a Cartesian plane (given their coordinates) and colour in the shapes (such as flowers and animals) that they define. This kind of problems has for the first time attracted the attention and interest of a student called Martina to mathematics. She is 15 years old, and a regular student in a mainstream secondary school near Treviso (Italy), though she has Down syndrome and severe language impairments, with a very small verbal vocabulary. She is unable to write much more than her name and even struggles to count up to ten, but she is able to copy letters and numbers. All mathematics tasks (e.g. operations with fractions and equations) are performed with the help of a scientific calculator and of a ruler to draw straight lines and to measure. We also discuss the mathematics achievements of a second student called Francesca: starting with algebra, she learned to solve problems in the areas of Nutritional Science and of Business Administration. The role of the inclusion in mainstream schools of every disabled student, regardless the severity of the disability, has been crucial for these results.

Stepping Stones To University

Ms Rachel High, Tutti Arts, AUSTRALIA

0109 NS HG23

My name is Rachel High, a 31 year old woman with Down Syndrome. This presentation will describe my experience of three years attendance at Flinders University supported by the Up the Hill Project. This experience is unique because the Up the Hill Project is the only one of its kind in an Australian University.

The Up the Hill Project is for people with an intellectual disability to participate in University life. My participation in the project will be described, along with the activities and supports provided

A PowerPoint Presentation will show evidence of the inclusive activities and events in which I participated during my attendance at Flinders University, concluding with the participation in the Graduation Ceremony at the end of the three years.

The outcomes, successes and personal benefits experienced during attendance at Flinders University will be outlined with a focus on the major collaborative

achievement of writing and directing a short film which came out of my enrolment in Screen Studies.

Providing opportunities to people with an intellectual disability to attend University is shown to be exceptionally beneficial and successful, but requires intensive support from family and community members.

The Way To Empowerment Of People With Down Syndrome Towards An Independent Lifestyle: Lessons Learned From Escuelas De Vida (Schools Of Life) And Viviendas Compartidas (Shared Apartments)

Pedro Oton Hernández, Down España, SPAIN

O110 NS HG23

Schools of Life, as theoretical framework and Shared Apartments, as practical implementation are an alternative for people with Down syndrome internationally to empower them to achieve an autonomous and most independent life.

Both projects were launched by the Fundación Síndrome de Down de la Región de Murcia a decade ago. Down España has been including these projects since 2004 and has created a National Network of Schools of Life, which now has 14 members all over Spain.

The School of Life is the theoretical framework proposing and supporting a new approach regarding people with DS (to develop any activity on early stimulation, education at all levels, learning opportunities, employment, leisure time, etc.) that recognizes the capacity of people with DS to take their own decisions and to gain control of their lives as far as possible. The Shared Apartments take into account the guiding principles of the School of Life and develop a psycho-educative, comprehensive and holistic model in three specific stages: training, development and assessment. This model is the basis for any teaching/learning process aiming at achieving an autonomous and independent life both for people with or without disability.

The results obtained at physical, social, emotional and cognitive level will be presented and we will open up a discussion on how the Schools of Life, developed through the Shared Apartments, facilitate the acquisition, development and maintaining of abilities and capacities leading people with DS to be able to control their own lives and be as much independent as possible.

Making A Connection- The Impact Of A Mentoring Program For Adults With Down Syndrome

Catherine McAlpine, Down Syndrome Victoria, AUSTRALIA

O111 NS HG23

Adults with Down syndrome often lack opportunities to further develop their skills and abilities and achieve greater independence. A mentoring program is a cost effective way of providing individualised support to adults with Down syndrome to create meaningful opportunities for skill development.

Mentoring Connections aims to create opportunities for adults with Down syndrome to develop networks and explore pathways to increase their independence. At the same time it works to improve understanding of the abilities of people with Down syndrome and their potential contribution to the community.

Real life relationship situations were created between mentors and mentees through one-to-one meetings and regular communication.

Participants took part in facilitated interactive group sessions exploring similarities and differences in the hopes and dreams of mentors and mentees. The concept of 'work' was explored through interactive playback and improvisational theatre.

The extension of social networks was beneficial for both parties. Regular interaction and communication provided new experiences and instilled greater confidence in adults with Down syndrome in new social situations.

A need for opportunities for adults with Down syndrome to establish social networks with their peers was observed. Mentors developed greater awareness of the abilities of adults with Down syndrome and their potential as valuable contributors to their community.

A one-to-one mentoring relationship is a mutually beneficial method offering adults with Down syndrome an opportunity to establish wider social networks that support personal growth.

Relationships with a solid foundation allow a safe and secure base from which to tackle the issues and challenges surrounding independence faced by adults with Down syndrome.

The Symbol Academy Showcase!

Baksi, L. & Colleagues, The Symbol Academy, Symbol UK Ltd, UK

O112 NS HG23

The Symbol Academy is a small independent special school set up by parents for secondary aged pupils who have Down's Syndrome in an area where there is a lack of appropriate statutory provision. Following in the footsteps of Dr John Langdon Down and his insights into the value of performing arts as a life experience and context for self expression and learning, our provision offers a performing art curriculum with opportunities to take part in a range of expressive arts as part of a group.

Staff and students would be delighted to show you our work.

The Influence Of Apolipoprotein E Genotype On The Age Of Onset And Duration Of Dementia In Individuals With Down Syndrome

N Mulryan, T Ongulusi, E Reilly, J Tyrrell, M Cosgrave, Z Hawi, M McLaughlin, B Lawlor, M Gill, M McCarron, Daughters Of Charity, IRELAND

O113 NS HG22

Down syndrome (DS) is the most prevalent chromosomal abnormality associated with intellectual disability. The syndrome has features associated with precocious ageing with a high degree of variability among different individuals. Life expectancy of people with DS has improved dramatically, however by 40 years of age virtually all individuals with DS have the neuropathological changes characteristic of an Alzheimer type dementia. Apolipoprotein E (Apo E) is a polymorphic protein which has been associated with the pathogenesis of Alzheimer type dementia with various allelic forms, namely 2, 3 and 4. A negative association has been demonstrated between exhibiting the Apo E4 allelle and the subsequent risk of developing dementia in people with Down syndrome. The purported benefits of possessing an Apo E2 genotype are less clear.

To determine the influence of Apo E genotype on the age of onset and duration of dementia in individuals with DS.

Eighty female subjects with DS and known Apo E allele status were assessed for the presence of dementia. Those diagnosed with dementia were followed longitudinally, many until the time of death. The age of onset of dementia and subsequent course and duration of the illness were studied with regard to Apo E allele status.

This study presents the assessment findings of those diagnosed with dementia and their decline over time.

Whereas positive Apo E4 status was associated with early and rapid decline in those with dementia the presence of Apo E2 appeared to be less protective in those older individuals with dementia over a prolonged course of illness.

An Audit Of Health Service Provision For Children With Down's Syndrome In The UK

Layden, EA (University Of Edinburgh); Jackson, PD (University Of Edinburgh/ Community Child Health Dept, Rhsc); DSMIG UK, University Of Edinburgh, UK

O114 NS HG22

Children diagnosed with Down's syndrome require medical follow-up and screening for a range of associated health problems. This audit looked at how the healthcare needs of these children were managed across the U.K.

To audit how healthcare is provided and whether medical surveillance guidelines are followed for children with Down's syndrome in the U.K.

A web-based questionnaire was distributed to clinicians in U.K. NHS Children's Services via email. (Telephone follow-up was subsequently required due to initial low response rate.)

There was a response rate of 34%. Of those who replied, 10% did not know how many children were treated/reviewed in their area, and 21% had no way of ensuring follow-up of all children with Down's syndrome. Most (86%) included children with Down's syndrome in a general neurodevelopmental clinic, rather than a separate Down's clinic. Over 40% of the children's services had other healthcare professionals present at clinics some of the time. The majority (85%) followed standard guidelines for medical surveillance, and all but two were aware of the Down's Syndrome Medical Interest Group's 'Guidelines for Essential Surveillance'. (20% of respondents were DSMIG members.) 40% of children's services audited their healthcare provision.

A significant number of Children's Services in the U.K. had no method of ensuring follow-up of all children with Down's syndrome, which is a cause for concern. However, where follow-up occurred, the majority followed appropriate guidelines for medical surveillance. Recommendations: institute uniform methods of ensuring appropriate follow-up of all children with Down's syndrome; audit parental perceptions of healthcare provision.

Is Early Onset Of Osteoporosis In Women And Men With Down Syndrome Based On Different Factors? Down Syndrome (DS) Is Associated With Many Biochemical, Metabolic, Immunological And Musculoskeletal Disorders

Professor Maria Sustrova, Slovak Medical University, SLOVAKIA

O115 NS HG22

The aim of this study was to evaluate bone mineral density (BMD) and find some of risk factors in young adults of DS in both sexes.

We examined 102 persons with DS (50F/52M), mean age W 25, 7±10 yrs, M 27, 8±10 yrs and 40 healthy men. We evaluate the concentration of 25-(OH) vitamin D, 1,25-(OH)2 vitamin D, FSH, DHEA-S and testosterone by Immonotech, BMD by dual-energy X ray absorptiometry.

Concentration of 25-(OH) vitamin D was significantly decreased in most subjects with DS, but not of 1, 25-(OH)2 vitamin D. The concentration of 1,25-(OH)2 vitamin D, were in women with DS significantly decreased as in men ($p<0,001$), also severe and moderate deficit was more often in women. The concentration of DHEA-S in DS men were significantly lower ($p<0,001$) and concentration of FSH were higher ($p<0,001$) that in healthy men, but not of testosterone. Decreased BMD had 60 % of men and 33 % of woman, but BMD and Z score were significantly decreased in men: FN BMD ($p<0, 05$), FN Z score ($p<0, 0001$), L1-4 BMD ($p<0,003$), Z score ($p<0, 01$). Bone mineral density of neck and lumbal spine in men correlated positive with concentrations of DHEA-S and FSH.

90,8% of persons with DS had 25-(OH)vitamin D deficit, in women deficit is severest. In men is low BMD more frequent (60 %) and is caused mainly by hypogenitalism – sexual immaturity and by vitamin D deficit. In both sexes of DS adults is a complex of other factors – changed bone markers and cytokines, health conditions, medication, low physical activity and dietary practices - which may contribute to the early incidence of osteoporosis.

This work was supported by Ministry of Health of Slovakia (No.2005/39-SZU-17)and CENDO.

Regression In Young Adolescents With Down Syndrome

Dr. Deirdre Cahalane, St. Michael's House, IRELAND

O116 NS HG22

5 cases of unexplained regression in young adolescents aged 12 to 16 with Down Syndrome are described. They were seen in a community based organisation for people with Intellectual Disability.

The individuals all presented with a gradual but marked decline in daily living skills, marked social withdrawal, a generalised slowing down of movements and speech ;and in some an apparent loss of speech.

To raise awareness and prompt further research into the causes and optimal treatment of similar cases. There is a limited amount of literature available to date

The extensive medical and neurological evaluation is described. Use of pharmacotherapy including antidepressants, antipsychotics and benzodiazepines , the possibilities and pitfalls are described.

Possible diagnoses including Obsessional slowness are considered. Prasher describes a similar regression in Down syndrome adults; 'Young Adults with DisintegrativeSyndrome ' {YADS}. Wing has described catatonia in autism, including a case with Down Syndrome.

The symptoms in Prasher and Wings series are very similar to the cases seen here. Although none of the children previously had a diagnosis of A.S.D. the regression was autistic like with withdrawal from others , a reduction or loss of speech, devellopment of abnormalities of movement .The deterioration in functioning and communication is devastating for parents of these children. That, coupled with uncertainty of diagnosis and treatment warrants further research .

Sleep Disturbances As A Tool For Early Intervention Against Cognitive Impairment In Children And Adults With Down Syndrome

Professor Jacqueline London, FRANCE

O117 NS HG22

Down syndrome is characterized by many developmental abnormalities including mental retardation which could be related at least partially to sleep disturbances. Sleep disturbances in early childhood of Down syndrome persons have been mostly underestimated especially on their consequences on physical and neural development.

Although sleep disturbances in patients with mental deficiency have already been reported in the early 70th, little attention has been used to improve the sleep quality of DS persons. More recently, the attention of sleep disturbances in the general population especially for OSA (Obstructive Sleep Apnoea) has been highlighted and

devices for this condition are now well used and are also used at a moderate rate for DS persons but only recently and in very few countries. Many recent reports from Australia, Italy, Hong-Kong, Spain, USA, have shown that 40-60% of children with DS aged 4 months and 6 years have OSA even if they do not snore and if their parents report not to have any sleep problem.

People with Down syndrome have not only sleep apnoeas but also sleep fragmentation (frequent sleep arousals without apnoea) and also sleep disorders breathing (SDB).

Murine models have provided some paradigm in future early intervention for improving mental retardation in DS. As mice present also almost the same sleep patterns as humans, it is possible to identify with DS murine models, the altered neuronal pathways. We will present data performed by us and others showing how sleep studies with trisomic 16 mice and transgenic mice for hSOD1 and hAPP genes might shed new light for a better understanding of the neural systems involved in sleep. These types of studies should give rise to new intervention pathways which might help persons with ESDL syndrome not only to get a better sleep but also to improve their skills and to prevent them from some adverse effects of their early ageing. We will also point out the need for professionals (physical therapists, nutritionists etc) to help the DS persons to have a better sleep.

Does audit & guidelines help improve the medical care & management of children with Down Syndrome?

Dr.S C Puri, Dr. I. Rawson, Child Development Centre, St. James's University Hospital, UK

0129 ME6

In 1998 the Down Syndrome Medical Interest Group U.K proposed evidenced based guidelines for basic essential medical surveillance.

Based on these guidelines we audited our services provided to children with Down syndrome. This highlighted inadequacies, subsequently an audit tool & database of children with Down Syndrome was established in 2004.

To determine if recommendations through guidelines & audit improve the quality of service delivered.

Audits were carried every two years; the findings were fed back to the service with recommendations. Comparisons have been through re- audit through four years.

The results of the audits are summarised as follows:

	2004	2006	2008
Growth Plotted	81%	94.6%	100%
Cardiac Status established	97.3%	97.3%	97.4%
Thyroid Function Tested	85.7%	97.3%	97.4%
Vision assessment	58.6%	86.1%	79.4%
Hearing assessment	80.6%	94.6%	100%
Cervical spine instability discussed	3%	43.2%	82.4%
Coeliac disease	3.7%	11.1%	8.6%
Dental Care discussed	3%	78.3%	82.4%
Social Issues discussed	24%	91.2%	33%

The results demonstrate that guidelines and audit does improve care & service delivery. There has been a successive improvement; however the vision assessments & discussion of social issues have declined. This reflects the withdrawal of the services from within the dedicated clinic due to lack of resources. We recommend a standardised format for follow up and an audit tool based on the guidelines to improve the medical surveillance & management of children with Down syndrome.

Medical Intervention in People with Down Syndrome - Portuguese Guidelines

Pinto M, Palha M, Andrade D; Portuguese Down Syndrome Association - APPT21, PORTUGAL

0133 ME6

Several countries have developed specific guidelines for the medical follow up of individuals with Down syndrome. However, they must be tailored to the unique characteristics of each country. The Portuguese Down Syndrome Association (APPT21) was responsible for the development of the Portuguese guidelines.

To present the Portuguese guidelines currently recommended by the Portuguese Down Syndrome Association.

We made a review of several guidelines from different countries and adjusted the recommendations to our country, taking into account that most people use private services, that we lack support from health visitors and that our population has a lack of information regarding health.

We have ambitious guidelines, trying to cover all medical areas and focusing on the importance of early detections of severe problems. Some aspects are not yet fully settled and are open to discussion.

We know that our recommendations have a tight schedule of follow up but that is also true for children without Down syndrome in Portugal. The cost versus benefits of this approach should be discussed. We hope that this presentation will help us to improve even more our medical intervention program in people with Down syndrome

Physical Activity in Adolescence

Dr Nora Shields, La Trobe University & TCD Dublin, AUSTRALIA / IRELAND

0130 ME7

This Session will explore the issues of Adolescence and physical activity which is vital for promoting good health and wellbeing

Social and Emotional Development of Adolescence with Down Syndrome

Professor Trevor R. Parmenter, Stewart Einfeld University of Sydney; AUSTRALIA

0131 ME7

This session will explore the social emotional development in adolescents with Down syndrome.

Adolescents Health and Development of Puberty

Professor Siegfried M. Pueschel, Consultant Paediatrician, Child Development Centre at Rhode Island Hospital in Providence, USA

0132 ME7

This session will explore the Health issues of Adolescence and pubertal development

The Image-Maker

Hard is the stone, but harder still
The delicate performing will
That guided by a dream alone,
Subdues and moulds the hardest stone,
Making the stubborn jade release
The emblem of eternal peace.

If but the will be firmly bent,
No stuff resists the mind's intent;
The adamant abets his skill
And sternly aids the artist's will,
To clothe in perdurable pride
Beauty his transient eyes descried.

Oliver St. John Gogarty
(Otolaryngologist)

Day Three

Friday 22 August 2009

Plenary lectures

Rooms of presentation are coded:
MH (MAHONY HALL)
TH (THEATRE)
BS AND CODE (BUSINESS SCHOOL)
NS AND CODE (NURSING SCHOOL)

Benefits of Inclusion and Keys to Success

Experiences of Inclusion for Pupils with Down Syndrome in Mainstream Primary Schools in Limerick City and County: Perspectives of Parents and Teachers

Ursula Doherty and Margaret Egan, Department of Special Education, IRELAND

PL18 MH

In recent years, there has been a significant increase in the number of children with Down syndrome attending mainstream primary schools in Ireland. While this trend towards inclusive education is supported by legislation and government policy, much has yet to be learned about how the inclusive process is managed in Irish schools.

This study explored the experiences of inclusion for pupils with Down syndrome in mainstream primary schools in Limerick city and county. Questionnaires were completed by principals and class teachers of 13 pupils with Down syndrome attending 11 primary schools and by nine parents of children with Down syndrome enrolled in primary schools. Responses were analysed to provide both quantitative and qualitative data.

Findings indicate that inclusion can be a positive experience for pupils with Down syndrome and for the entire school community. It can contribute to the creation of a more caring and tolerant ethos where diversity is understood and accepted. When provided with the necessary supports, pupils with Down syndrome have the capacity to participate, learn and achieve in an inclusive learning environment. The opportunities afforded by inclusive education for pupils with Down syndrome to make friends and to learn with and from their peers were highly valued by the parents and teachers who took part in this study.

Data also highlight a number of issues that need to be addressed to enable pupils with Down syndrome to realise their potential in mainstream primary schools. These include: the availability of multi-disciplinary assessment and support; the provision of professional development courses for teachers; building partnerships with parents; inclusion in the mainstream curriculum and approaches to the organisation of support teaching.

Results have important implications for the ways primary schools are resourced and supported. In particular, they underline the need for primary teachers to be provided with opportunities to develop their expertise and skills in educating pupils with Down syndrome in mainstream schools.

In response to these findings, an Education Resource Pack for primary teachers of pupils with Down syndrome has been devised by the Department of Special Education, Mary Immaculate College in collaboration with the Special Education Support Service, Department of Education and Science. This publication, which was funded by the Teacher Education Section of the Department of Education and Science, will be distributed to all primary schools in Ireland in September 09.

Encouraging Literacy at Home and School

Gillian Bird, Director of Education and Information at Down Syndrome Education International, UK

PL19 MH

The session will present an overview of research into reading achievements and suggest expectations for achievements for children of differing abilities across the age range. Effective teaching methods at different stages in literacy development will be summarised with practical examples for learning to read and write with comprehension at home and at school. The benefits of supported literacy and how to use reading activities to promote speech and language development will be included.

Encouraging Social Inclusion & Managing Behaviour

Dr. Kathleen M. Feeley, Associate Professor of Education, USA

PL20 MH

For many individuals with Down syndrome, engaging in challenging behaviours prevents them from accessing inclusive opportunities within their schools and communities. Training educators in the functional assessment process as well as providing them with strategies to develop positive behaviour support plans can drastically reduce problem behaviours in individuals with Down syndrome helping to ensure their success in inclusive schools and communities.

Transition From School - Adult Ongoing Education

Dr. Patricia O'Brien, Foundation Director of National Institute for Intellectual Disabilities (NIID), IRELAND

PL21 MH

The purpose of this presentation is to share the experiences of students with intellectual disabilities gaining access into a university setting, specifically Trinity College Dublin to complete a two year course entitled, Certificate in Contemporary Living. The perceptions of the students, family members and tutors were captured through focus groups, questionnaires, use of photo voice and document analysis. The student voice echoed by that of family members and tutors found that inclusion within a university setting led the students to see themselves more alike than different to their same aged undergraduate peers. They felt more accepted, more competent and more socially networked. Vital to the development of friendships was a mentoring programme. The aspect of the Certificate programme that supported students to participate in a range of undergraduate classes will be described as well as the role that service agencies have played in supporting the programme. Being included within a university setting opens up a whole new way of being for students who have previously experienced marginalization. Such inclusion is a cogent way to promote ability. The work of the National Institute for Intellectual Disability (NIID) to roll out the programme throughout Ireland will be reported upon.

Providing a Range of Living Options

Professor Roy McConkey BA, PhD, Professor of Developmental Disabilities School of Nursing, University of Ulster, NORTHERN IRELAND

PL22 MH

Although a range of living options is required to meet the diverse needs of people with Down Syndrome, the greater challenge is ensuring that these deliver the outcomes that people desire. There is growing evidence that a better quality of life is more often found with individualised, community-based support options. The reasons

for this are less clear but go beyond the available funding resources. Key elements are identified based on present research and promising lines for future enquiry are identified in our quest for cost-beneficial support services in the modern era.

Quality and Family Quality of Life for People with Down Syndrome: Issues of adolescent and adult life

Professor Roy Brown, Professor Emeritus, University of Calgary, in Canada & Flinders University, Australia, CANADA / AUSTRALIA

PL23 MH

This lecture introduces the concept of quality of life and what it means over the life span to adolescents and adults with Down syndrome. The highlights include individual choices, inclusive opportunities, and the development of friendship, partnership and marriage. Also considered are the issues of family quality of life and the relationship between parents and the young person as they develop and experience life. The balance between care, risk taking, with opportunities and lifestyle are presented across life domains.

Independent Community Living On Being Included in the Community

Professor Steve Eidelman, President, The American Association of Intellectual and Developmental Disabilities, USA

PL24 MH

People with Down syndrome bring value and diversity to communities everywhere. Buoyed by Article XIX of the UN Convention, policymakers, advocates, family members, professionals and people with Down syndrome are seeking improved methods of supporting adults living with Down syndrome in communities worldwide.

Old notions of continuum of care and varying program models are continuing segregation, isolation and separation of people with Down syndrome, particularly adults, from their communities. In many places people with Down syndrome are needlessly institutionalized. Presumptions of competence and capability are ignored.

Professionals and policymakers frequently confuse buildings where supports take place with the level of support needed by people with Down syndrome to function and indeed thrive in communities. The research is clear that people with intellectual disabilities prosper when they live in places of their choosing, and that congregate care, regardless of how we label it, diminishes quality of life and functional capabilities over the long run.

Article XIX, while not requiring deinstitutionalization, has a strong bias towards supporting people in community. Whether based upon a human rights approach, or a clinical/programmatic approach, community living is the direction in which services and supports for people with Down syndrome are to be delivered. Strategies and policy implications of the shift from congregate to community-based care and supports will be presented.

Increasing Employment Options

Ms Anne O'Bryan, expert in developing, managing, and improving services for individuals with learning difficulties in the United States and Europe, UK

PL25 MH

This presentation will introduce four initiatives aimed at increasing the likelihood of people with learning disabilities getting and keeping valued careers. The first one, the Valued in public action learning event is for public sector employers and is aimed at improving the way they attract, select and employ people with learning disabilities in their organisations. The second initiative is Cincinnati Children's Hospital model, Project SEARCH. This is an internship for young people in their last year of school in a large prestigious employer such as a hospital, local authority or bank. During the year the young people learn complex, systematic tasks in a variety of departments making them a useful talent pool from which the employer recruits permanent staff. The third initiative is an employment awareness raising and signposting service for people with learning disabilities and their families. It helps individuals develop their own employment pathway using the existing employment opportunities and services in their local area. Finally Family Led Jobs is an initiative for families who are not finding the career support they need for their family member. It is a series of workshops with individual support that combines Personal Futures Planning and Customised Employment to individually negotiate successful careers. All four initiatives have been introduced in Bath and North East Somerset over the last year.

The presentation will be a short introduction to each initiative. The "Meet the Expert" session will go further into any of the initiatives as required.

Meet the Expert

Benefits of Inclusion and Keys to Success

Responding to the Specific Needs of Pupils with Down syndrome in Mainstream Primary Schools: Building on Strengths and Addressing Needs

Ursula Doherty and Margaret Egan, Department of Special Education, Limerick, IRELAND

ME15 NS HG20

This practical session is a follow-up to the presentation outlining the results of a study of educational provision for pupils with Down syndrome in mainstream primary schools in Limerick city and county. It will provide details of an Education Resource Pack that was developed in response to key findings from the study. These findings highlight the importance of helping teachers to enhance their abilities to meet the specific needs of pupils with Down syndrome. A range of strategies that take account of the profile of strengths and learning needs associated with Down syndrome will be presented. These have been devised to maximise participation and learning for pupils with Down syndrome attending mainstream primary schools in Ireland.

Encouraging Literacy at Home and School

Gillian Bird & Professor Sue Buckley, Director of Education and Information at Down Syndrome Education International, UK

ME16 BS Q121

The session will address evidence for the benefits of inclusive education, describe planning requirements and elaborate on teaching practices for successful inclusion. It will share research findings of gains in spoken language skills, reading and writing, math, general knowledge and in social independence for children included in regular education classrooms. The model of inclusion in the UK and factors for success, including attitude, training and working in partnership with parents will be described. The session will provide guidance for planning at the individual level, with examples of adaptations and resources for learning through a differentiated curriculum for children with a wide range of abilities at primary and secondary schools. The workshop will give participants the knowledge and confidence to develop inclusive education in their community schools.

Teaching Children to Read

Professor Sue Buckley, Down Syndrome Education International, UK

ME17 BS QG13

Many children with Down syndrome can achieve useful reading and writing skills - often reading is a strength and better than might be expected from other skills. Learning to read can begin in preschool years and will also develop spoken language and working memory skills. It can also open doors to work and independence.

This session will enable participants to meet Sue Buckley and ask about current research. Sue has been researching reading, memory and language development since 1980. The main aim is to share successful teaching strategies and show examples of achievements across the ability range. Sue will also aim to give everyone an understanding of how reading skills develop and why they help speech, language and memory skills.

The session will cover strategies for introducing reading in early years, developing reading, decoding and spelling strategies, developing reading comprehension - at home and at school. It will also cover linking reading to language, and how to develop literacy across the curriculum. The session will be illustrated with video material. Material from a new instructional video developed at DownsEd will be shown.

Participants should learn enough to start to teach a child to read or to develop a child\'s reading. Questions and discussion will be welcomed.

The session will be of value to parents and professionals working with children from 2 to 17 years. All children can benefit from being involved in shared reading and reading instruction - even when they do not become independent readers.

Encouraging Social Inclusion & Managing Behaviour

Dr. Kathleen M. Feeley, Associate Professor of Education, USA

ME18 NS QG27

Challenging behaviour can be effectively addressed by the implementation of a four component positive behaviour support plan consisting of strategies to address setting events, antecedent strategies, skill based strategies, and appropriate consequence strategies. During this session, a series of case studies will be introduced illustrating the implementation of positive behaviour supports (from preschool through junior high-school) and how they led to successful inclusion of students with Down syndrome in general education settings.

Transition From School - Adult Ongoing Education

Dr. Patricia O'Brien, Foundation Director of National Institute for Intellectual Disabilities (NIID), IRELAND

ME19 TH

In this session Dr. Patricia O'Brien will be joined by students, family members, and tutors from the NIID who will explore the content, the delivery and the outcomes for students with intellectual disabilities completing the Certificate in Contemporary Living which is offered by Trinity College, Dublin. As part of the presentation a DVD will be shown on one student's journey in undertaking the course. Past students will report on those aspects of the course that they found the most memorable and what the course has led to for them in terms of work and other options associated with lifelong learning.

Providing a Range of Living Options

Professor Roy McConkey BA, PhD, Professor of Developmental Disabilities, School of Nursing, University of Ulster, NORTHERN IRELAND

ME20 BS QG15

A Quality of Life Framework is proposed for assessing and monitoring the living options that are available internationally to people with Down Syndrome, including living with family carers. Particular emphasis is placed on addressing the shortcomings that are currently evident across most options, notably community integration, valued social roles and poverty. These provide an agenda for achieving modern support services than transcend old models of residential care provision.

The Application of Quality of Life Principles and Family Quality of Life in the Context of Adolescents and Adults with Down Syndrome

Professor Roy Brown, Professor Emeritus, University of Calgary, in Canada & Flinders University, Australia, CANADA / AUSTRALIA

ME21 MH

This represents a detailed follow up of the prior plenary lecture. It includes both presentation and discussion of the key components of quality of life approaches, and their application in social situations. It examines how inclusion may be improved and achieved through a quality of life approach. This represents a challenge for all of us in the ways we tend to think and help people with Down syndrome. It represents a life span issue in terms of problem solving. Issues discussed include the values of the family, the choices that are made, the rights of individuals in terms of choices, the development and structure to choice situations, and the practical implications that arise in terms of planning and decision making over the lifespan.. The session provides opportunities for questions and answers, as well as broader discussion, so that different views, values and approaches can be considered within a quality of life framework for people with Down syndrome.

Independent Community Living

Professor Steve Eidelman, President, The American Association of Intellectual and Developmental Disabilities, USA

ME22 NS HG23

For people with Down syndrome, the possibilities for living a life much like their peers without Down syndrome is quite possible. Perhaps the term independent living needs to be replaced by something else for none of us, with or without a disability, is truly independent.

During this session we hope to have a lively dialogue about strategies and techniques to support adults with Down syndrome to live a life that is more like than different from their age peers. Cultural variations and customs abound, but principles of living in a community can transcend cultures.

The temptation is to engage in programmatic models of services for people who we label as being different. The intent of this session is to discuss and explore strategies that are individuals based and that can be generalized into systems of are, not program models.

Increasing Employment Options

Ms Anne O'Bryan, expert in developing, managing, and improving services for individuals with learning difficulties in the USA and Europe, UK

ME23 NS HG22

This presentation will expand on the four initiatives aimed at increasing the likelihood of people with learning disabilities getting and keeping valued careers.

This "Meet the Expert" session will further explore any of the initiatives as required.

Oral Presentations

Inclusion As Easy As A Day At The Beach: The Camp Pals One-To-One Model

Josh Stein, Mount Sinai School Of Medicine; Jenni Newbury, Princeton University, Camp Pals Organization, USA

0118 BS QG15

The lecture will discuss the merits of the non-classroom based inclusive experience provided by Camp PALS, a week-long sleepaway camp for teenagers with Down syndrome.

After attending the lecture, attendees will reconsider the orthodoxy of inclusion and have the ability to create low-cost, high-impact programs that either augment or substitute for traditional inclusion practices.

Pioneering a one-on-one model in which every camper is paired with an individual counselor of a similar age, Camp PALS maximizes the interaction between young adults with Down syndrome and those without. The model allows campers to achieve a new level of socialization with their typical peers as well as others with disabilities. It also offers an educational experience to counselors, college-aged youth with little familiarity with Down syndrome.

Qualitative data and anecdotal evidence have shown the program to be highly successful in creating a positive, lasting effect on participants. Individuals with Down syndrome improve socialization skills and increase their confidence while the volunteer staff becomes dedicated advocates and catalysts for change.

The PALS model presents a reproducible, high-impact, low-cost model that provides long-term benefits for youth with Down syndrome.

Parental Perspectives On An Innovative Summer School

Andy Loebus, Jennifer Shields, Down Syndrome Research Institute, CANADA

0119 BS QG15

in 2005, and modelled after the Down Syndrome Research Foundation. DSRI's mission is to investigate, implement and promote educational approaches that help individuals with Down syndrome experience success and independence at school, with friends, and in the world of work. DSRI runs summer schools and homework clubs, conducts research, and does professional development with teachers and other professionals.

DSRI's growth has been dramatic: enrolment in DSRI's flagship summer school has increased by more than 500% over 5 years, and there are plans to open DSRIs in five other communities around Ontario. What makes the DSRI model so popular? What needs has it met? DSRI has conducted regular research with parents to discover the answers to these questions.

The DSRI team conducted telephone interviews and surveys with parents to elicit their opinions on many aspects of the DSRI summer schools.

how DSRI has met the

This session will be of interest to people who are engaged in organizing to meet the needs of young people with Down syndrome and their families.

Down Syndrome, Cognitive Function And Aging

London J., Universite Paris Diderot, FRANCE

0120 BS QG13

It is generally accepted that DS adults are at higher risk for Alzheimer disease (AD) than the general population because they have biochemical hallmarks similar to those of AD even during childhood. Nevertheless they do not develop signs of the dementia early in life and for those who may develop dementia later there is a considerable variability in age of the clinical signs onset which may be delayed by 10 years or more. Moreover some individuals with DS do not develop dementia.

The aim is to search for the cognitive and behavioral profile of DS which may be related to early changes in AD and to use animal models for both DS and AD to better understand those signs. Some of the genes that are overexpressed in DS produce proteins critical for neuron and synapse growth, development and maintenance which may lead to developmental cognitive deficits but paradoxically with aging, may participate in molecular cascades supporting neuronal compensation.

A survey of those signs and the main results obtained with AD and DS animal models to underline the possibility of some compounds to improve cognitive impairment as early as it is possible.

We will present common signs in early AD and DS. We will show results of the role of some genes present in triplicate in DS for some characteristics of both DS and AD (enlarged endosomes, APP abnormal metabolism, abnormal phosporylated Tau proteins, abnormal NGF transport, abnormal processing of AchE).

We will present the results already obtained for some compounds with animal models of AD and some which are on Phaes II trials for patients

The already or nearly tested compounds in animal models of AD should be tested in animal models for DS. We are sure that the many progress in AD pharmacology will help our delighted DS persons who really need that basic research also will help them. Adults with DS may be a unique group of individuals to promote successful agents against brain aging in the general population.

Age Related Health Patterns Among People With Down Syndrome In Europe

Ryan D, Hall L, Noonan Walsh P, Fingleton M., Centre For Disability Studies, School Of Psychology, University College Dublin, IRELAND

0121 BS QG13

Health disparities are evident when people with Intellectual Disability are compared with their peers. While life expectancy among people in this segment of the population is increasing, they are likely to incur age-related physical and mental health risks. To date, people with ID, specifically people with Down Syndrome (DS) have been mostly absent from public health scrutiny in Europe.

To identify age related health patterns in people with DS in 14 countries of Europe who were participants in a wider study that applied a set of health indicators devised to measure aspects of the health of adults with ID.

Information on demographic characteristics, health status, health determinants was gathered using the POMONA Survey Protocol. Participants were N=158 individuals

with DS. Data was collected by means of face to face interviews, telephone surveys and postal surveys.

Data were analyzed according to 3 age-groups: 19-34, 35-54 and 55 years and older. Frequency of sensory and mobility impairments as well as oral health problems, mental health problems, BMI and presence of epilepsy increased with age. Frequency of health checks increased with age while uptake of some checks e.g. testicular examinations was low.

Findings suggest that a dedicated set of health indicators has some utility in identifying age-related health patterns among European adults with DS with results suggesting an increase in the frequency of health problems with age. Further developments in building reliable, sustainable health information systems are needed to inform policy and health service providers.

Moving On From The Medical Model Of Down Syndrome

R. Grant. Senior Policy Analyst, Saskatchewan Ministry Of Education, CANADA

0122 BS QG13

The use of the medical model of Down syndrome has been in place since its description by Dr. Langdon Down in 1866. This model has lead to much advancement in recent decades for persons with DS, primarily regarding medical research and access to medical care. However, in today's context this model is seen by many to be outdated. The use of a social or rights-based model of DS is more likely to increase real inclusion for people with DS into all aspects of life, including a reduction in selective termination based on prenatal determination of DS. We will present and advocate for a definition of Down syndrome as a naturally occurring chromosomal arrangement that has always been a part of the human condition. This session will

is not a condition (specifically) in need of medical intervention. With broader global inclusion of people with Down syndrome it is important to note that Down syndrome is not a disease, disorder, defect or medical condition. Down syndrome

that in 2009 the greatest challenges for many individuals with Down syndrome are public and governmental perceptions that underestimate their potential and abilities and therefore limit them from full inclusion as called for under the recent UN Convention.

The Responsive Teaching Curriculum

Gerald Mahoney & Frida Perales, Case Western Reserve University, USA

0123 NS HG20

The purpose of this presentation is to provide an overview of Responsive Teaching, a recently published early intervention curriculum (Mahoney & MacDonald (2007), PRO-ED publishing). This evidence based curriculum is designed for parents and professionals. It focuses on parents using responsive interaction strategies as a means fro promoting children's active participation in the course of daily routine activities.

This presentation will:

1) Describe the five components of the Responsive Teaching curriculum: Responsive Teaching Interaction Strategies; Pivotal behavior Intervention objectives; Discussion Topics for explaining intervention; pivotal behavior profiles for assessing the effects of the intervention; and the RT Planning and Tracking program
2) Describe and provide videotape illustrations for several responsive teaching strategies
3) Describe published research findings that point to the effectiveness of this curriculum.

Research on a sample of 50 dyads indicated that children with disabilities made dramatic and statistically significant improvements in their cognitive communication and social emotional functioning after using Responsive teaching over a one year period of time. The effectiveness of the intervention was dependent on parents learning and using RT strategies in their routine interactions with their children. Responsive teaching is a commercially available curriculum that provides an effective intervention for addressing the developmental and social emotional needs of young children with Down syndrome.

Education For A Lifelong Smile

Hennequin M, Faulks D, Collado V, Mazille MN, Veyrune JL, University Of Auvergne, FRANCE

0124 NS HG20

The functional and anatomical characteristics of Down syndrome have direct repercussions on oral health as indirect consequences on social functioning.

The aim of this presentation is to review special education programmes that help to prevent the consequences of Trisomy 21 on oral functions and on oral hygiene, leading to increased autonomy and social integration.

Examples will be presented to illustrate a comprehensive approach to oral motor regulation therapy, oral hygiene, pain expression and education for participation with dental treatment.

Due to the accumulation of problems in the population with Down syndrome, it is necessary to specifically target this population to ensure equity.

Many of the oral health problems induced by Down syndrome might be reduced by occupational therapy, appropriate dental and orthodontic treatment, and by improving the attitudes and knowledge of parents, carers and professionals. The costs of these education programmes should be discussed in relation to potential compensation, which in turn depends on local socio-political choices.

Supporting Social Communication - Is Autism Being Over-Diagnosed

Sue Buckley, Gillian Bird, Julie Hughes, Becky Baxter, Stephanie Bennett, Angela Byrne, Michèle Pettinato. Down Syndrome Education International, Portsmouth, UK

0125 NS HG20

In recent years, the number of children receiving a dual diagnosis of autism and Down syndrome has increased. The use of standard screens for autism may over-estimate the incidence, as some behaviours which may indicate autism may be common in children with Down syndrome but not associated with autism.

This study aims to explore the incidence and natural history of behaviours used to identify autistic spectrum disorders (ASD) in children with Down syndrome. Two categories of behaviour are important: 1. Social behaviours which fail to appear, such as pointing and 2. Unusual behaviours which appear such as finger twiddling. We do not have normative data on either category of behaviour to tell us when to worry and to guide diagnosis.

Records of the progress of 40 children, aged between 18 and 42 months at the start of the study, have been collected over 12 months. Each child has been screened using the M Chat and parents have completed the Carey Temperament Scale. Children at risk have completed a play test. Each child has been assessed twice on the Bayley III at a 12 month interval and language and hearing records collected.

Results will be analysed to explore the presence of autistic indicators in this group and the relationships with cognitive, language and temperamental factors.

The results will be discussed in terms of understanding social communicative

development of children with Down syndrome. We hope that the study will prevent wrong diagnosis but also will contribute to correct early diagnosis of ASD.

Transition - A Story Of Success

Ally Attwell & Debbie Rickard, Voice Thru Your Hands Charitable Trust, NZ

0126 NS HG23

Transitions can be daunting for both parents and children. When the child has special needs it can be even more so - however it doesn't have to be. A few simple guidelines can make all the difference.

From a mother's perspective hear the trials and tribulations of supporting her daughter to succeed in the education system. She will explain the ups and downs of the transition process from early childhood to school and how this impacted on Tarryn's education or lack thereof.

Ally's desire to have all three children at the one school initiated the second transition from school No.1 to Whakarongo School.

The IEP process is the key to successful transition and inclusion. Hear how the authentic partnership between the school, the family, and Ministry of Education lead to an effective IEP meeting where Tarryn's successes were celebrated!

Share in the joy of a success story and go away with the motivation to be able to achieve your own authentic partnerships and avoid the potential abuse and power differential that this family no longer endures.

Find out what works in relation to successful transitions and inclusive practices.

How open communication and a collaborative approach provided an effective environment for learning and development to occur within a regular classroom.

Meet Tarryn and see first-hand her accomplishments.

As a result of Tarryn's successful inclusion into a regular classroom, her mother wanted to advocate for other children and set up the Voice Thru Your Hands Charitable Trust.

Modern Approach To Child Inclusion In Russia : From Parents Initiative To Professional Care For Children With Down Syndrome

Veronique Garrett - Downside Up Trustee, Russian Charitable Fund, RUSSIAN FEDERATION

0127 NS HG23

Democratic reforms that have been carried out in Russia promoted modern approach to child inclusion. The tremendous contribution to the development of services for families with Down syndrome has been made by the NGO sector since 1990. Despite of positive changes, people with Down syndrome in Russia still face daily discrimination, as well as strong barriers to education, employment, recreational activities, family life and participation in community life.

In 1996 Downside Up was set up to improve a quality of life for Russian children with Down syndrome. It was founded by the parents initiative to cover the lack of EI care existed in Russia. Started to render support to 45 families DSU provides now direct EI care and information support to 1200 families from Russia and ex-soviet republics.

DSU works to translate family-focused model of EI care all over Russia. In 2008 DSU started to issue a multidisciplinary journal "Down Syndrome in the 21st Century" aimed at promoting collaboration among professionals and to raise awareness of potential of people with Down syndrome in Russia. The journal covers contemporary Russian and foreign research and practice in Down syndrome in the fields of genetics, medicine, education, psychology, employment.

Due to extended collaboration between DSU and state institutions in Moscow, child abandonment has decreased from 95% in 1997 to 50% in 2006 and 80% children with Down syndrome has access now to pre-school education.

Extension of International cooperation between Russian-speaking professional community and foreign colleagues will provide opportunities to better child inclusion.

Peer Interaction In Mainstream Classes

Anne-Stine Dolva, Anders Gustavsson, Helena Hemmingsson, Lillehammer University College, NORWAY

0128 NS HG23

The objective of this qualitative study was to explore peer interaction in school activities that included pupils with Down syndrome together with their peers without disabilities in order to identify enabling conditions.

Six children with Down syndrome, each of whom was the only one with Down syndrome in a regular class were observed and interviewed.

Two main patterns of interaction were identified; equal and unequal interaction. Enabling conditions were found to be related to the nature of the activities in which the pupils interacted. The findings revealed how peers applied diverse enabling strategies to include the pupil with Down syndrome.

The results of this study highlight how activities and enabling strategies of peers may increase opportunities for peer interaction to take place.

JO MILLS MEMORIAL LECTURE

International UN Rights of People with Disabilities

Professor Gerard Quinn, Professor of Law and Director of the Centre on Disability at the National University of Ireland, Galway, IRELAND

PL 26 Helix

THANK YOU

My thanks to Mum, my thanks to Dad, to all
Who give my life its treasures. Thank you for
The part you play in my sweet joys and pleasures.
Who gave me songs, and gave me dance, and life
And sun forever.

Thank you for the tears you shed – the silent
Pain and sorrow; until the shadows fell
Behind, and light dawned with the morrow. Until
That time we all joined hands and faced our fears
Together.

I'm not an angel – just a child – but please
Don't fret and worry. Please take a break and
Watch me take my own small steps to glory.
Just look and see the hope that's mine and if
The future's like the past then surely I'll
Be fine.

Ann Dempsey June 2005

Posters

Health

Down Syndrome And Immune Abnormalities

Lyne Tremblay/Lynn Rastelli/Mary Pothos/Children's Hospital Of Eastern Ontario, CANADA

P1

Previous research in this population has identified several defects in both humeral and cellular immunity. A clinical study of children with Down syndrome in a community setting which documents the correlation between infection rate and severity and known laboratory immunologic abnormalities in this population has not yet been established.

To determine the incidence of immune abnormalities and the correlation with infection rate in a cohort of children with Down syndrome under the age of 18 years followed in a regional Down syndrome clinic in Ontario, Canada.

A prospective study utilizing an inception cohort of children with Down syndrome followed at the Children's Hospital of Eastern Ontario from Jan 2002 to Apr 2003. Immunologic testing was done once during this time period when the child was infection free for 6 weeks. A weekly symptom diary was completed by the family for one year.

Low levels of WBC (34%), lymphocytes (24%) and PMNs (16%) were documented in 64 children sampled. Low levels of CD3 (74%), CD4 (60.4%), CD8 (86%), CD19 (91%), and CD16/56 (53%) were found in 43 children sampled. Correlation with rates of infection from symptom diaries will be described .

Our study confirms a high incidence of immune abnormalities in the pediatric DS population, however, there was no correlation between serious infections and the immune abnormalities described.

Adults With Down Syndrome Are At Reduced Risk Of Cutaneous Melanoma: Results From A French Study

Daniel Satge, Laboratory Of Pathology, Centre Hospitalier 19000 Tulle, FRANCE

P2

The frequency of cutaneous tumours is not well known in persons with Down syndrome (DS).

Review of cutaneous melanoma in DS in France and in the published literature.

This review comprised 3 steps. First, we searched for cases of cutaneous melanoma in the records of 1,417 adults with DS aged 20+years at the Institut Jérôme Lejeune. Disease progression was evaluated. Next, INSERM data (Institut National de la Santé et de la Recherche Médicale) were reviewed to identify melanoma deaths during the period 1979-1999 in persons with DS for comparison with the general population by standardized mortality ratio. Finally, a review of the literature was performed to identify other reported cases of melanoma among persons with DS.

Two subjects at Institut Jérôme Lejeune developed a cutaneous melanoma; a 45-year-old woman with a melanoma of the finger, and a 29-year-old man with melanoma of the foot. The melanomas were removed by surgery and both patients are alive, without progressive disease, at 13 and 3 years, respectively.

Review of the INSERM data indicated 2 observed melanoma deaths where 7.081 were expected (SMR 28.24; 95%CI: 3.42, 102.03), suggesting a more than 3-fold decreased risk.

In addition, the review of the published literature identified a further 6 reported cases of melanoma in DS, bringing the total to 10 cutaneous melanomas, and no case of non-cutaneous melanoma.

On the basis of this review, persons with DS seem to be at reduced risk of cutaneous melanoma.

Thyroid Disease In Down's Syndrome Children: TSH Screening In Scotland Using Dried Blood Spot Samples 1997-2007

Jeremy Jones, Arlene Brown (Scottish Newborn Screening Lab), Joan Mackenzie (Scottish Newborn Screening Lab), Kath Leyland (Southbank Child Centre, Glasgow) and Malcolm Donaldson (Royal Hospital For Sick Children, Glasgow) UK

P3

Thyroid function surveillance is justified in Down's syndrome (DS) because of the increased incidence of autoimmune thyroid disease. Since 1997 dried bloodspot samples from DS children have been analysed for elevated thyroid stimulating hormone (TSH) levels, indicative of possible thyroid function changes.

Samples are processed in the national newborn screening laboratory. The current method is the AutoDELFIA neonatal hTSH fluoro-immunoassay (cut-off 4mU/L). Results above the cut-off trigger referral to a named paediatrician and clinical and biochemical assessment, including venous thyroid function and autoantibody tests.

In 1997 183 children were screened, with 10 children referred from two Scottish regions. By 2007 the uptake of screening had increased to 602 from 15 different areas. Between 1997 and 2007, 106 children have been referred with TSH elevation at a median age (range) of 10.14 (0.03-17.91) years. Median (range) capillary TSH elevation at referral was 5.69 (4.0-169.0) mU/L. Thyroxine treatment was started in 55% of referrals. Using cumulative data (1997-2002), the prevalence of hypothyroidism in Scottish DS children was calculated as 6.7% with a median annual incidence of 2.4% after the first year of life.

Dried blood spot TSH screening is widely available. Capillary sampling is easily performed, minimising trauma. Acceptability to both children and clinicians, and feasibility is reflected in increasing uptake. Children with mildly raised TSH and normal free T4 can be left untreated while maintaining or increasing surveillance. Annual screening using the newborn screening laboratory is an effective method of detecting developing thyroid disease in DS children.

Neurodevelopmental Impact Of Congenital Heart Defects In Down Syndrome

Jeannie Visootsak, MD, Lillie Huddleston, EDS and Stephanie Sherman, PhdD, Emory University School Of Medicine, Atlanta, GA, USA

P4

Nearly half of all children with Down syndrome (DS) are born with a congenital heart defect (CHD). Atrioventricular septal defect (AVSD), the most common form of CHD in DS, occurs in 38-60% of children with DS and CHD, but is observed in only 1 in 10,000 live births without DS. This represents a dramatic 2,000 fold increase in risk for AVSD among individuals with DS compared to those without DS; yet, virtually no studies have examined their neurodevelopmental outcomes.

This study is the first to characterize the early developmental profiles of children with DS and AVSD (DS+AVSD) compared to age-matched children with DS without CHD (DS-CHD).

Participants consist of 2 groups: 6 subjects with DS+AVSD (mean age 15.4 months) and 18 subjects with DS-CHD (mean age 15.6 months). The Bayley Scales of Infant and Toddler Development III was administered by a psychometrician who was blinded to each subject s cardiac status. The Bayley III was administered to the DS+AVSD group after cardiac repair.

The DS+AVSD group exhibited lower composite scores in all domains relative to their age-matched DS-CHD, with the cognitive and language domains showing significant differences, $p < .05$. The motor, social-emotional, and adaptive composite scores

were not significantly different between the two groups.

Our preliminary cross-sectional data document that children with DS+AVSD have greater developmental delays especially in the language domain, compared to children with DS-CHD. Implications for outcome and treatment are discussed. Studying young infants with DS+AVSD allows us the opportunity to identify variables linked with early deficits that may lead to further delayed development.

"Doctor, My Child's Turned Orange!" - A Case Series Of Hypercarotenaemia In Children With Down's Syndrome

Hurley M, Martin K, Marder E, Nottingham University Hospitals, UK

P5

Hypercarotenaemia is a benign condition causing an orange discolouration of the skin. It has been previously reported in association with increased carotenoid ingestion, hypothyroidism, diabetes mellitus, eating disorders, liver disease and due to an inborn error of metabolism. Animal studies have demonstrated that thyroxine is required for the conversion of carotene to vitamin A. It is therefore possible that in the hypothyroid state carotenaemia results. Details of the pathways involved remain elusive as does the mechanism behind the association of both hypothyroidism and carotenaemia with Down's syndrome.

To present a series of children with Down's Syndrome who presented with hypercarotenaemia and to explore the possibility that this association shares a common pathway with the aetiology of hypothyroidism.

The casenotes and laboratory results of three children with Down's Syndrome presenting with orange discoloration of the skin were reviewed.

All three children were found to have elevated â-carotene levels during the period of orange discoloration. One was found to be hypothyroid at the same time and one after a time lapse of four months. â-carotene levels in both normalized with improving Thyroid Stimulating Hormone levels.

We suggest that in children with Downs' syndrome presenting with yellow/orange skin discoloration investigations include â-carotene, vitamins A and E and liver and thyroid function. The evolution of an orange hue should prompt the clinician to check thyroid status as, in one of our illustrative cases, fluctuation in skin discoloration alerted clinicians to deteriorating thyroid control and led to a review of thyroxine dose.

Is Fatty Acid Intake And Metabolism In Children With Down's Syndrome Different When Compared To Their Non-Affected Siblings?

Brierley N, Amadorbueno A, Lehane C, Neville N & Crawford M., Institute Of Brain Chemistry & Human Nutrition, London, N7 7DD, UK

P6

Increased incidence and earlier onset of Alzheimer's disease (AD) is well-recognized in Down's syndrome (DS). The reasons for this are poorly understood. In the elderly a diet rich in omega-3 has been shown to reduce the progression of both dementia and AD. Could diet be a significant factor in AD in DS?

To compare fatty acid (FA) intake and metabolism in children with DS, and their non-affected siblings.

Cross sectional study with recruitment via DS Research Foundation and support groups. Inclusion criteria: Confirmed DS, siblings if available used as controls. A 7-day food record was completed for each subject and analysed using Foodbase V4. Blood samples from each child were analysed for FA using thin layer and gas chromatography, and mass spectrometry.

Dietary analysis showed all children with DS (17) and controls (15) met daily FA recommended values, regardless of FA supplementation.

Blood analysis showed a significant difference in metabolism of several FA but particularly in Vaccenic Acid (18n7:1) in DS compared to controls: RBC ethanolamine phosphoglyceride 0.087 vs. 0.798 ($p<0.01$) and plasma choline phosphoglycerides 1.582 vs 1.256 ($p<0.001$).

Children in both groups met their nutritional requirements for FA, however children with DS had significantly higher levels of vaccenic acid a monounsaturated FA in both plasma and red cells suggesting an altered metabolism of this FA, which has been associated with aging. Further investigations are needed, especially over time to establish if this is an important factor in Alzheimer's disease in DS.

Disclosure Of The Diagnosis Of Down Syndrome

Lynn Rastelli RN BSCN, Lyne Tremblay RN, Mary Pothos MD, Asha Nair MD, Children's Hospital of Eastern Ontario, CANADA

P7

The disclosure of Down syndrome is an enormous challenge for most physicians and known to have a lasting effect on parents. Nearly a decade ago a survey was completed by parents measuring their level of satisfaction with the disclosure. Instructive seminars on providing disclosure have been given to health care professionals in this region since that time. Eight years later, have we improved?

To assess the current level of parental satisfaction of the disclosure of the diagnosis of Down syndrome. To compare the current level of satisfaction with the previous results obtained in 2000.

A survey was mailed to all families (58) who had children born with Down syndrome between years 2005 and 2008 in the catchment area of the Children's Hospital of Eastern Ontario, Canada. The survey gathered both quantitative and qualitative data. The data collected related to timing of disclosure, setting, resources provided, terminology used in the disclosure, and overall satisfaction.

Of the respondents, 66.6% expressed overall levels of satisfaction with the disclosure. Qualitative comments from the parents included some of the following: "First and foremost, she is a baby that needs love and attention." "More 'like' other children than 'different'. Alternatively, one parent said; "Some of the positive information on Down syndrome would have been nice to hear."

Overall levels of satisfaction with disclosure have improved as compared to our previous survey in 2000. There are still elements of the disclosure that can be improved and specific recommendations will be highlighted. There seemed to be a therapeutic effect for parents by sharing their experience of the disclosure with us by participating in this survey.

Diagnosis Communication

A Biasotto, T M Sgaramella, L Nota, C Baccichetti, Fondazione Baccichetti per la sin, ITALY

P8

The time when the parents are told that their child has down syndrome, maybe the first impact for the parents with the disability, and they thought to it like a lonely unlikely situation. From there we want deepen this theme because communication of diagnosis is a very delicate moment resolutely for the positive evolvement of the baby as well connected to the enhance life expectancy for the people with Down syndrome.

The aim of this study is to do an actual view about how is lived the communication of diagnosis by the parents of children with Down syndrome, and what changes the

method used to communicate it carry on in the family context

To examine these aspects, we propose an interview by questionaire to 46 parents (22 male 24 female) of children with Down syndrome aged between 0 and 3 years; we ask them to say an assessment about how they received the communication of diagnosis.

Data display that only 50% think to have received a professional or a middling professional communication of diagnosis, and 47% of the parents reputes it a positive experience. Additionally 39% say that the partner has a positive reaction to the event. In the study we expand on the relation between a professional communication of diagnosis and a positive reaction to the event.The utility of this study is that the medical and nurses staff to have a feedback by the parents of the baby about they live the communication of diagnosis and in what aspects they have to enhance their job of relationship with the parents

In conclusion also if the satisfaction of parents is better than previously described we must pay more attention to give to the parents a more updated description of what it means to have Down syndrome

Diagnostic Overshadowing: The Role Of The Multidisciplinary Team

Donna Heerensperger, RN BSCN; Anita Wamsley, BSCPT (C), Alberta Children's Hospital, CANADA

P9

In the 2002 Report of the Surgeon General's Conference on Health Disparities and Mental Retardation , Dr. Spitainik, PhD noted that individuals' health needs are frequently interpreted only in reference to their MR and not in regards to broader issues. Beyond negative perceptions and issues involving stigma, this "diagnostic overshadowing" continues to limit access to appropriate and quality care.

The Down syndrome Clinic at Alberta Children's Hospital in Calgary, Canada provides multidisciplinary support to children with Down syndrome and their families. This presentation, through the use of a case study will examine the role of the multidisciplinary team in supporting families and advocating within the medical community when the diagnosis of Down syndrome may be influencing access to care.

The case study involves an infant who presented with low tone and generalized weakness. The infant was content and easy going, placed few demands on the caregivers and had normal feeding, weight gain, and bowel and sleep patterns. The parents concerns centered on the infant's slow progress (despite frequent multidisciplinary team appointments) and her protruding abdomen.

As developmental delay and low muscle tone are "expected" with children with Down syndrome, the family felt their concerns were not being heard. The presentation will focus on the team's journey of looking beyond the diagnosis of Down syndrome, honoring the family's instincts, and advocating on their behalf so that the diagnosis of Teratoma could be made.

The Medical Diagnostic Challenge Of Trisomy 21

Dr S C Puri, NHS Leeds Leeds PCT, UK

P10

Children with Down Syndrome have an increased susceptibility to a number of medical conditions, which can be difficult to diagnose due to the complexity of the case and the difficulty at times to get an accurate history & examination due to contributing learning difficulties.

We present a case presentation of child with Down Syndrome with a challenge to diagnose her medical presentation.

A seven year old Caucasian girl with Down syndrome three weeks post emergency cardiac surgery for left ventricular outflow tract obstruction presented with reluctance to walk, weight loss, day time enuresis. Systemic and neurological examination was normal.

Investigations revealed low haemoglobin, reticulocytosis, high ferritin, high LDH and CRP, 38. positive ANA.

Echocardiogram, liver function, renal function & thyroid function tests were normal. Blood, urine & stool culture were negative. Urine microscopy was normal. She had a normal bone marrow biopsy. Normal abdominal ultrasound. MRI Brain & were reported normal apart from an incidental finding of an arachnoid cyst. She was assessed by neurologists, neurosurgeons, cardiologists, haematologists and the rheumatologists.

Four months post presentation she continued to have weight loss & became wheel chair bound.

The case history was re-considered and investigations repeated. A repeat ECHO & blood cultures suggested sub-acute bacterial endoccarditis. She was treated with intravenous antibiotics for six weeks. She made a full recovery. Two years later, aged nine she presented with pubic hair but no menarche or thelarche, with normal LH and raised prolactin levels between 1150-1901. She has been assessed by the neurologists & endocrinologists. Re-investigations have not revealed an aetiology for this finding leaving us with a diagnostic challenge.

It is important to keep re-considering the clinical history & presentation and consult widely till a diagnosis is achieved.

Education Program In Sweden For Healthcare Professionals

Pia Enestrom & Katarina Moen Lindberger, The Swedish Down Syndrome Association, SWEDEN

P11

In Sweden, the birth of a child with Down syndrome is often associated with some sort of crisis of the parents. The extent of the crisis is often related to nursing at the hospital. Nursing, well-functioning and supporting, is important for the family's well-being. Adequate, up-to-date description of Down syndrome is essential to make the birth a positive experience. Physicians are uninformed about the positive potential for children with Down syndrome and this lack of knowledge affects the ability to provide good care.

The project aims at giving health care professionals information on Down syndrome from a parent's point of view and also to work as a link between health care professionals and families.

Interviews and discussion forums have been performed with parents in order to understand state-of-art concerning today's nursing. Lectures have been held for health care professionals, followed by inquiries in order to investigate their needs.

This project shows the need for continuous education of health care professionals in order to take good care of parents and their social network.

We can see a great lack in up-to-date knowledge and a need of competence development.

There is an importance of feedback and the medical staff appreciates this feedback. Unfortunately, most education is given of medical reasons and involves too seldom the patient's perspective.

Health care professionals need to be informed about the positive potential for children with Down syndrome in order to give good care.

Nursing could be improved through continuous feedback from parents.

Down Syndrome Health Concerns In Kuwait

Sadika A. Alawadi, Ministry of Health/Genetic Center, KUWAIT

P12

Down syndrome (DS) is a worldwide problem, and it is the most common cause of mental retardation. The incidence of DS in kuwait ranges from 1.1 to 3.6 per 1000 births. They had many health problems in regard to heart and GIT which need surgical intervention as well as thyroid dysfuncton.

Several studies had been done to evaluate the epidemiology, metabolic, endocrinal and The other associated problems of the syndrome.

Cytogenetic profile of DS patients, assessment of thyroid function, complete blood picture, admission profile, immunoglubulins and echocardiography were done. Added to that epidemiological studies were carried out.

The total number of DS patients in a period of 29 years (1979-2008) is 1722 (927 males and 795 females). 97.2% of cases were of regular type. Consanguinity was positive in 601 cases (34.9%). 17% of DS patients had overt hypothyroidism, and subclinical hypothyroidism in 30% of patients. Hypozincemia played a role in hypothyroidism.

Down syndrome patients are a major chromosomal disorder in Kuwait as well as a big health problem, so Kuwait Medical Genetic Center was established to take care of those people as well as the other genetic disorders.

Thyroid Function In Down Syndrome - Case Review Of A Portuguese Paediatric Hospital

Castro S, Pinto M, Amaral D, Lopes L, Pina R, Fonseca G; Hospital D Estefania, CHCL, Lisbon, PORTUGAL

P13

Thyroid dysfunction is more prevalent in children and adolescents with Down's syndrome. The diagnosis of hypothyroidism can be difficult since the symptoms can be wrongly attributed to Down syndrome. Growth velocity must be calculated and any slowing down must be valued. Thyroid screening tests are recommended in children and adolescents with Down syndrome but treatment indications are not consensual.

To study thyroid dysfunction in children and adolescents with Down syndrome attending a Portuguese Paediatric Hospital.

Retrospective review of all the patients with Down syndrome attending both child development and endocrinology clinics, between Januray 2004 and May 2008. We evaluated growth and thyroid function tests, treatment options and follow-up.

Forty-five patients with Down syndrome we included in our review. Nineteen (42%) had thyroid dysfunction and in most cases (13 out of 19), sub-clinical hypothyroidism was found. In our cohort, thyroid dysfunction increased with age, was more frequent in females and had non-specific symptoms. When needed, treatment showed good results.

Prevalence of thyroid dysfunction in children in adolescents with Down syndrome in our population was similar to other studies (30-50%). In these patients the challenge is when to treat sub-clinical hypothyroidism. Although not consensual, treatment seems to improve activity, humour, growth velocity and cognitive functioning and benefits should be discussed.

The Age Distribution Of Onset Of Celiac Disease

Pothos M, Nair A, Tremblay L & Rastelli L, Children's Hospital Of Eastern Ontario, CANADA

P14

Celiac disease is being recognized more commonly in the Down syndrome (DS) population with an estimated prevalence of 5%. However, more information is required about the age distribution of onset of celiac disease, natural history and associated comorbities in the DS population.

To determine the prevalence and age distribution of onset of celiac disease in a community based cohort of children with Down syndrome followed in a regional Down Syndrome Clinic at the Children's Hospital of Eastern Ontario (CHEO), Canada.

We performed a retrospective chart review of all patients followed at CHEO's DS Clinic from the clinic's inception in 1992 to December 2008. Greater than 97% of the children with Down syndrome living in the CHEO catchment area are followed in this clinic from infancy to age 18 years for their routine DS related medical care. Routine celiac screening is done at ages 2-3 years and repeated subsequently every 2-3 years until age 18 years.

354 patient charts were reviewed. 18 (5%) patients were diagnosed with celiac disease, initially from positive celiac screening, and subsequently confirmed by biopsy. 78% of patients developed celiac disease between ages 6-12 years with negative celiac screening prior to that age. 50% of patients had associated hypothyroidism and/or insulin dependent diabetes as autoimmune comorbidities prior to the development of celiac disease.

Further epidemiologic studies are needed to determine the best timing for screening of celiac disease in the Down syndrome population. DS individuals with associated hypothyroidism and/or IDDM need closer surveillance.

Alopecia Areata Is A More Frequent Complication In Children With Down Syndrome

Wolfgang Storm, St.Vincenz Hospital Paderborn, GERMANY

P15

Alopecia areata is a more frequent complication in children with Down syndrome being observed with a higher incidence than in the general population. Some of the resumed etiologies are vitamin A and zinc deficiency and hypothyroidism, but most of the cases are considered to be an autoimmune disorder.

731 patients of our Preventive Medicine Clinic for Children with Down Syndrome (children up to the age of 18 years) were surveyed in regard to the diagnosis of alopecia.

17 (2,3 %) had episodes of alopecia areata. Causative factors could be found in two (sequelae of the treatment of lymphoblastic leukemia and celiac disease, respectively). In 15 patients no apparent etiologic mechanisms could be found.

Nevertheless, 13 children were successfully treated (one with celiac disease by a gluten free diet and 12 by homoeopathic treatment). To find specific options of therapy it is important to look for causative mechanisms; for symptomatic treatment homoeopathy is a frequent alternative in our experience.

Prevalence Of Malocclusion In A Sample Of Mexican School Children And Adolescents With Down Syndrome

López-Morales Patricia, CD., López-Pérez Rubén, CD, MO., Borges-Yáñez S. Aida, CD, MPH, DO., De La Fuente-Hernandez Javier, CD, MSP., Valdespino-Echauri Leticia, LIC. Facultad De Odontologia, Universidad Nacional Autonoma De Mexico, Integracion Down IAP, MEXICO

P16

Dental occlusion is the correct relationship between maxillary and mandibular teeth as they come into functional contact. Malocclusion refers to abnormal tooth alignment. Occlusions can be divided into three types by Angle's classification method: A Class I is considered the ideal occlusal relationship, the upper teeth slightly overlap the lower teeth. Class II is identified by the lower anterior incisors positioned significantly behind the upper anterior incisors when biting down. Class III is identified by the lower anterior incisors positioned edge to edge with, or just in front of the upper anterior incisors.

To determine the prevalence of dental malocclusion in a sample of Mexican school children and adolescents with Down syndrome (DS).

In a cross-sectional study in 57 Mexican children and adolescents (34 males and 23 females) aged 3-15 years with DS from a special education school were examined. Malocclusion according to the Angle classification, in terms of the molar relationship, was determined using plaster dental models.

The results showed a prevalence of malocclusion of 45.8%, Angle Class I was represented by 54.2%; followed by Class III (32.7%) and Class II (13.1%).

The data demonstrate a high prevalence of malocclusion in the studied sample. Therefore, children and adolescents with malocclusion should receive the opportune and appropriate dental treatment because a correct dental occlusion is essential to ensure an optimum oral health.

Management Of Reflux And Constipation: Should We Recommend Activities To Address Posture And Tone And Promote Core Stability?

Baksi, L. & Colleagues, Symbol UK Ltd, UK

P17

Practitioners at the Down's Syndrome Association National Specialist Eating and Drinking and Swallowing clinic and elsewhere have found a high incidence of persisting gastro oesophageal reflux and constipation amongst children with Down's syndrome who present with eating and drinking difficulties. Reflux and constipation are recognised as contributory factors to eating and drinking difficulties.

These eating and drinking difficulties are evidenced by tolerance of a highly restricted diet and range of presentation of food and drink.

Difficulties and stress around meals and diet for these children and families may preclude commonly recommended strategies- such as increasing fluid intake and foods that promote intestinal transit for constipation, and reducing intake of high fat foods such as fromage frais for reflux.

Literature on reflux in infants indicates that the condition reduces as children's postural patterns mature, and within yoga practice, postures where the abdominal muscles are contracted are recognised as helping to move the bowels.

We would like to take the opportunity arising at this congress to discuss with practitioners from a range of professional backgrounds whether there is an evidence base for recommending addressing motor patterns and posture as a 'treatment' for constipation and reflux, and specific advice on approaches, such as physical handling strategies, positioning, sensory integration therapy, yoga asanas, motor activities.

Growth In Children With Down's Syndrome And Heart Malformations

Rohrer T, Stierkorb E, Lehmann-Kannt S, Seebald C, Gortner, L. University Children's Hospital, Homburg, GERMANY

P18

Children with Down's syndrome (DS) have well-documented growth retardation and an increased incidence of heart failure, a known cause of short stature. DS is associated with congenital malformations, with heart malformations being the most frequent in children with DS. Heart malformations are found in approximately 40–60% of DS patients.

To investigate the effect of heart malformations on growth and weight in children with DS.

In a retrospective cohort study, data were collected from German children with Down's syndrome by means of a standardized questionnaire. Statistical analyses were carried out using a linear test model. $p<0.05$ was considered statistically significant.

We analysed 7823 growth data sets from 1032 children with Down's syndrome (53.5% boys and 46.5% girls). The frequency of heart malformations in this cohort was 53%. The appearance of heart malformations in the first year of life was found to have a significant impact on growth ($p<0.05$) and weight ($p<0.001$). Between the ages of 2 and 5 years, height was not statistically decreased in children with heart malformations ($p=0.704$) but their body weight was ($p<0.05$). No difference in height was noted for children aged 6 to 10 years with heart malformations ($p=0.58$) but weight remained lower ($p<0.01$).

Children with Down's syndrome and heart malformations show significantly decreased height and weight in the first year of life. After correction of the defect, usually during the first year of life, children show catch-up growth, but body weight remains lower.

Survey On Gastrointestinal Issues In Children And Adults With Down Syndrome

Maureen Gavin RN, BC CDDN, Paul Patti M.A., & Nancy Andiloro M.A., New York State Institute for Basic Research in Developmental Disabilities, USA

P19

In children and adults with Down syndrome (DS), gastrointestinal symptoms are often under-reported and are therefore often not treated.

The Gastrointestinal Symptoms Survey was developed to assess the prevalence and degree of gastrointestinal problems in children and adults with DS. The survey assessed the incidence of gastrointestinal issues, including food sensitivities, intolerances, allergies, and the health history of the individual and their family members.

The survey was distributed to parents and caregivers of children and adults with DS in the United States, Canada and the United Kingdom

The survey sample consisted of 317 children and adults with DS. The survey findings indicated 53% reported one or more food allergies or intolerances. Survey findings indicated on a weekly basis: 5% had diarrhea, 7% had constipation, and 3% had bowel incontinence. According to the survey findings 6% were diagnosed with celiac disease, and 5% were diagnosed with irritable bowel syndrome.

It is imperative to assess and raise the awareness of gastrointestinal issues in children and adults with DS. Gastrointestinal problems in people with DS can occur at any age and must to be assessed and addressed. According to recent studies and literature, one of the most common under-diagnosed diseases in children and adults with DS is celiac disease.

Considerations On Undescended Testes In Children With Down Syndrome

Wolfgang Storm, St.Vincenz Hospital Paderborn, GERMANY

P20

There are reports in the literature of an up to 50 % incidence of undescended testes in men with Down syndrome.

Based on 195 male patients of our Preventive Medicine Clinic for Children with Down Syndrome we want to consider therapeutic strategies especially in regard to the subsequent risks of fertility and malignancy.

A survey of the diagnosis of undescended testes was made among 195 male children with Down syndrome beyond the age of two years.

We had findings demanding therapeutic procedures in 56 patients (29 %),but only 13 patients had had hormonal treatment (7) or orchidopexy (6), respectively.

Indications for the treatment of undescended testes in children with Down syndrome have to be reconsidered to prevent potential risks such as infertility and malignancy.

Achondroplasia And Down Syndrome: A Case Report Of A Rare Association

Santos S., Silva T., Pimentel M.J., Pinto M.; Centro De Desenvolvimento, Serviço De Pediatria, Hospital Dona Estefânia, Lisboa, PORTUGAL

P21

Achondroplasia and Down Syndrome is a rare association of two independent disorders, that has only been reported few times previously. They are distinct genetic diseases, but with overlapping features such as short stature, developmental delay or hypotonia.

To present a clinical case of this rare association to highlight the difficulties found and to help others in the future to deal with these cases.

We report the case of an 8 year old girl, born from a mother with achondroplasia and a healthy father. Since achondroplasia is dominantly inherited, the child was expected to have the disorder, but at birth she also had features of Down syndrome as confirmed later by kariotype. We review the evolution of this child both regarding physical health as well as cognitive functions and adaptive behavior during her 8 years of life. We address the problems resulting from the additional burden of having two disorders, and how they can be overcome.

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We report this case not only because the association of these two diseases is unusual, but also to show how the overlapping clinical features may complicate management and follow up.

Health Problems In A Group Of 143 Adults With Down Syndrome In France

De Freminville B, Parisi K, Dupre Latour R, Touraine R, Centre Hospitalier Universitaire - Hopital Nord, FRANCE

P22

Life expectancy of people with Down syndrome increased dramatically during last years. In addition, they present an increased risk to develop several medical problems that are often overlooked.

In a large group of adults with Down's syndrome, we wish to 1) evaluate health status and health access, 2) measure their social and cognitive abilities, and 3) draw their medical, educative and rehabilitative histories;.The participants have been seen for a consultation with a parent or educator. The study include questionnaires for medical history, medications, sleep, behaviour problems (Reiss Scale), adaptative capabilities (Vineland), dementia signs (Geydie) access to health system, supports during their life, employment, housing and leisure. The patients had a medical examination, several biological tests, and were evaluated with Raven's colored progressive matrices.

Between 2005 and 2008 we have seen in our outpatient Down syndrome clinic, 143 adults, 72 women and 71 men. The average age is 38,5 years (20 to 72 years). Several medical and dental problems were detected (hypothyroidism, celiac disease, cataract, deafness, sleep apnea, Alzheimer disease, . . .). We found also difficulties of healthcare access for this population. Details will be given.

This study confirms the necessity of regular appointment for people with Down syndrome with specific preventive checks. Along these lines, for every person with Down syndrome, a medical electronic file that contains all the important information to be shared between MD, would be worthwhile.

Comprehensive Intervention In People With Down Syndrome

Miguel Palha MD, David Andrade MD, Mónica Pinto MD, Teresa Condeço PSY, Luísa Cotrim PSY, Susana Martins PSY, Raquel BarateirO PSY, Filipa Costa SPEECH THERAP., Portuguese Down Syndrome Association/Child Developmental Centre Diferenças, PORTUGAL

P23

The Portuguese Down Syndrome Association together with its Child Development Centre - DIFERENÇAS – have devised a comprehensive set of Intervention Programmes designed to provide children with DS with training methods that will effectively improve their skills in various key areas: fine and gross motor skills, phonological awareness, math and working memory abilities. They will also foster the development of self-help skills, social abilities, emotional development and training for employment.

To make known the Early Intervention programmes which are currently available for children and parents; to highlight the need for on-going research on DS issues and on the design of teaching methods tailored to the specific needs of people with developmental disabilities.

Presentation with a few of the intervention programmes in a multimedia format.

Over the years, families and the very communities have acknowledged the positive impact that the Child Development Centre has had both in terms of early intervention, counselling and teaching guidance, but also for its stance in favour of inclusion. It also shows the benefit of a multidisciplinary team, working together to provide a whole range of support to children with disabilities.

It is advisable that support should be provided by a multidisciplinary team of professionals who will better able to deal with the unique issues facing children with DS and help them achieve their full potential.

Optical Quality Is Implicated In The Poor Visual Performance In Down Syndrome: Comparing Different Measurements Of Visual Acuity

Little J-A(1), Woodhouse J.M.(2), Saunders K.J. (1) & Lauritzen J.S.(1)
1. Vision Sciences Research Group, Biomedical Sciences, University of Ulster, NORTHERN IRELAND, 2. School of Optometry & Vision Sciences, Cardiff University, Cardiff, Wales, UK

P24

Down syndrome (DS) is associated with reduced visual acuity that cannot be explained by clinically evident pathology, lack of motivation or attentional factors (Woodhouse et al., 1996; John et al., 2004). In order to isolate the contribution of the optics of the eye to visual acuity, we measured grating resolution acuity and AMSJB LMR ?RRCLB latter technique effectively bypasses the optics of the eye.

Methods: 29 children with Down syndrome, aged 9-16 years participated in the study. 68 age-matched developmentally normal children acted as controls. All wore optimal refractive correction and none had clinically evident ocular pathology. Both measures used a two-alternative forced choice psychophysical technique.

Results: Grating resolution acuity and interferometric acuity did not change significantly with age in either group. Both grating resolution and interferometric acuity were significantly worse in the DS group compared to controls. The mean grating resolution acuity for the DS group was 4.1 times poorer than the control group. This is a substantial reduction compared to interferometric acuity, which was reduced by a factor of 1.3 in the DS group compared to controls.

Discussion: Both grating resolution and interferometric thresholds are reduced in children with Down syndrome. However, the discrepancy between developmentally normal children and those with DS is much greater for grating resolution acuity.

Conclusions: These differences suggest that optical factors play an important role in reduced visual acuity in DS.

Oral Health Promotion - Working Together - The Way Forward

Dr Maura Cuffe, HSE Dental Services, IRELAND

P25

The Irish Society for Disability and Oral Health was founded in 2002. One of the society's aims is to promote links with organisations representing people with disabilities. Contact with Down Syndrome Ireland established that there was a demand for information on oral health from parents.

To work with Down Syndrome Ireland, to develop an information resource on Oral Health and Down Syndrome

The project was proposed to a HSE Oral Health Promotion Committee as some committee members also held executive positions in ISDH. It was agreed that the brochure would be developed by the HSE committee in consultation with DSI and ISDH, as a free download on the three organisations' websites. Subsequently, if funds allowed, the brochure could be graphic-designed.

Following a literature review, draft text was circulated by email internally (HSE) and externally (DSI and ISDH). A draft brochure was produced. DSI supplied the cover photo (with parental consent). More email consultations followed and the final agreed version was approved by HSE Communications. Access to email was pivotal in facilitating the necessary consultations.

The consensus brochure "Oral Health and Down Syndrome" will be available from the three organisations involved. It will also be distributed through HSE Dental Clinics, DSI branches and ISDH meetings. Each organisation will shortly be able to upload the brochure to their websites and print copies.

Promotion of oral health in people with Down syndrome is an important factor in good health management. The involvement of DSI was crucial in ensuring that the needs of the target audience were heard and hopefully met.

Early Development

Down Syndrome And Automatic Processing Of Emotional Facial Information: Implications For Their Social Life

Guadalupe Morales & Ernesto Lopez, Universidad Autonoma De Nuevo Leon, MEXICO

P26

Research on mental retardation is a key component to understand the relation between cognitive and emotional development (Sroufe, 1998). One of the most relevant genetic conditions to explore this relation is the Down syndrome for several reasons. For example, persons with Down syndrome (DS) are characterized as highly emotional individuals (Smith & Walden, 1998). This behavior may be related to a dysfunctional neural architecture. However, the consequences of this dysfunctional neural on the cognitive emotional architecture remain at large unknown.

The goal was to look for deficits on automatic and non automatic evaluation mechanisms of emotional information on DS individuals.

Participants with Down syndrome (DS) and control subjects were tested in two affective priming studies. The first one required subjects to recognize emotional faces with a short SOA (300 ms). The second one included an indirect measure of affective priming associated with an attention task with a long SOA (2000 ms).

The principal result was the observation that DS participants do not recognize negative information at short SOAs (automatic evaluations) and that these individuals report significant slower latencies than control subjects to facial recognition through all experimental conditions.

Implications of these results to appraisal theories of emotion as well as behavioural therapy are discussed.

Keywords: Down syndrome, affective priming, facial recognition.

Integration Of People With Disability Experiences In Down Syndrome

Sustrova, M., SLOVAKIA

P27

The authors of this TV document "Ways of hope" prepared special Christmas programs about the children and adults with Down syndrome from Down Syndrome Centre in Bratislava as a message of peace and love.

Document presented early intervention programs with a wide variety of services provided by specialists.

Among the services most often required by children with DS are speech, physical and occupational therapies.

Children with DS benefit from the same community programs as other children do, such as play groups, nursery school, swimming and music lessons, dance classes and other social activities. Children learn to play and work with peers, make friends and rivals, get into trouble and learn to take responsibility for their behavior. Youngsters with DS acquire new skills and develop individual talents as they grow, benefiting from all life experiences as well as their innate abilities. There are individual differences in the development of all children and adults.

The authors shows several examples from Slovakia where the youngsters were able to be integrated in the normal mainstream of education and employment. Some of them are well known persons in sport events (Special Olympics). Although parents of children with Down syndrome have access to considerable support, no specialist, friend, or book can offer their child what she or he needs most the love, care and encouragement of a family.

The Early Support Of Basic Linguistic Competences And Communication Skills

Professor Dr. Etta Wilken, GERMANY

P28

Children with Down's Syndrome show specific problems both in the motor-functional as well as in the cognitive and social area of linguistic development. It is therefore necessary to begin as early as possible with speech therapy treatment in order to influence in good time the syndrome specific handicaps.

Sign-language is especially for the young child a key to understand the world – and for his parents and peers it is a window to the world of the child. A relevant additional aspect is that during the time when the biological window for leaning words and grammar is open, the child has an alternative instrument – and when he is able to speak he has only to switch the mode.

"Precomunication Program" – Promoting The Early Communication Skills Of Children With T21, In The First Year Of Life

Teresa Condeço Psym, Luísa Cotrim Psym, Sofia Macedo Psym, Miguel Palha MD, Fernando Ramos PhD, Margarida Almeida PhD, Portuguese Down Syndrome Association/Child Developmental Centre Differences, PORTUGAL

P29

The APPT21/Child Developmental Centre Differences have developed, since 1992, an Intervention Program aimed at promoting communication in children with Down Syndrome. The Programs methodology has been improved over the years with new strategies, intended to develop cognitive and communication skills based upon their developmental characteristics.

In our presentation, we propose to highlight the main features of the "PreComunication Program", its methodology and strategies and the software developed to facilitate children performance.

The "PreComunication" Program was designed to promote the early communication skills of children with T21. This Program includes information about: what is Total Communication; the early use of natural gesture and enhancement of joint attention. We also present "Sign Language Workshop", an interactive multimedia application intended to be an essential support for parents, educators and therapists working with children with Down's syndrome in early intervention programs.

Early Intervention Programmes are structured in weakly sessions. Several activities and strategies that stimulate communication development are established for each weakly session and the caregivers are taught how and when to perform the gestures, so that they can use them effectively. Caregivers are also responsible for teaching the gestures to other family members and to kindergarten staff.

Sign Language workshop is an essential support for our early intervention program. In our days we used it in

- Cognitive Disorders: Downs Syndrome
- Language disorders without cognitive impairment
- Pervasive Developmental disorder: Autism spectrum (mainly to enhance prelinguist interactions and early pragmatic skills including turn-taking and joint-attention)

Demographics

Down Syndrome In The Netherlands, England/Wales And Ireland - Past And Prospects; A Demographic Model

Gert De Graaf (Department Of Orthopedagogics, University Of Gent; Dutch Down Syndrome Foundation), Jeroen Vis (Department Of Cardiology, Academic Medical Centre, Amsterdam; Interuniversity Cardiology Institute Of The Netherlands, Utrecht), Meindert Havema, Dutch Down Syndrome Foundation and University of Gent (Belgium), NETHERLANDS

P30

The Netherlands are lacking reliable empirical data in relation to the development of birth and population prevalence of Down syndrome. For the UK and in Ireland there are more historical empirical data available.

A theory based model is developed for predicting Down syndrome prevalence in The Netherlands from the 1950's onwards. It is likewise applied to Ireland and the UK for the purpose of validation. Furthermore, a prediction to 2050 is constructed.

Maternal age births data in the general population, maternal age related risk of Down syndrome, data on selective abortions and mortality rates (from 50 studies from the 1930's until today) were obtained to create this model.

The model shows a good fit with historical empirical data, notably four UK and two Irish population prevalence studies and nine birth prevalence studies. For The Netherlands, birth prevalence is estimated at 14 per 10.000 with around 275 total annual births. The impact of selective abortion is lower than in the UK. Dutch Down syndrome population prevalence is estimated at 7.7 per 10.000 and the grand total at 12.600 individuals. The prevalence of 'older' persons with Down syndrome (over 40 years of age) in the Netherlands will reach a peak in 2010, a doubling compared to 1990, implying an increased demand on medical care and counselling.

A theory based model for Down syndrome prevalence can provide supplementary data in situations with a lack of empirical material and be used for understanding and predicting long-term developments.

Determining The Prevalence Of Persons Living With An Intellectual Disability In Nova Scotia

Dr. Deborah Norris, Mount Saint Vincent University, CANADA

P31

There is a lack of reliable information available on the prevalence of adults living with an intellectual disability in Nova Scotia, as well as their current and future health and social service needs. Answering questions about current and future gaps in health and social services for this population is integral to informing public policy and improving the health and overall well-being of Nova Scotians with an intellectual disability and their families.

The purpose of this presentation is to review the progress of the Intellectual Disabilities Service Needs Research Alliance in determining the prevalence of adults living with intellectual disability in Nova Scotia, Canada, along with their current and fu

The strengths and limitations of the alliance and the data collection process established in Nova Scotia will be reviewed.

The population-based estimate of adults living with an intellectual disability within

Halifax Regional Municipality, Nova Scotia will be reviewed and results from the first and second wave of data collection in Nova Scotia will be discussed. Lessons learned will also be shared.

Accurate, reliable, accessible, and comparable regional information about persons living with an intellectual disability is needed to inform the policy and planning process associated with provision of services for this population, their families, and their communities.

A Survey Of Experiences Of People With Down Syndrome In New Zealand

Susan Foster-Cohen, Michelle Davey, Annie Horton, Anne Van Bysterveldt, The Champion Centre, NZ

P32

Families of children with Down syndrome must have a voice if all children are to reach their full potential.

To understand the experiences of children and adults with Down syndrome in New Zealand through a survey of parent members of the New Zealand Down Syndrome Association.

A 32-item mailed survey to the 473-strong membership of the New Zealand Down Syndrome Association sought information about early intervention, primary and secondary education and post-school experiences; about children's joys and frustrations in a range of areas of their lives; and about the level and quality of services available in New Zealand.

181 (38%) of the questionnaires were returned representing all regions of the country and children aged from under a year old to 50 years. Parents rated communication difficulties as their highest concern with concomitant concerns about social integration. Parents rated social integration as amongst the greatest sources of both joy and frustration for their children and provided eloquent analyses of the barriers to their children's self-esteem. Parents were frustrated with having to fight for services and educate the professionals; with the lack of respite care and supported living arrangements; with the limited funding of professional services particularly teacher aides and speech therapists; with difficulties around employment; and with regional inequalities in service provision.

Though parents celebrated the very real achievements of their children in a range of arenas (academic, sporting and artistic) it is clear there remain significant barriers to every child with Down syndrome in New Zealand reaching their full potential.

Epidemiology Of Down Syndrome

Stella Forti: Audiology Unit, Fondazione Irccs Ospedale Maggiore Policlinico, Mangiagalli E Regina Elena; Umberto Ambrosetti: Department Of Dipartimento Di Scienze Chirurgiche Specialistiche, University Of Milan, ITALY

P33

In literature the ratio of Down Syndrome (DS) newborns is usually 1:1,000. A lot of papers relate none differences about geographical distribution or differences for race. Instead there are many researches about the epidemiology of DS in different countries.

Aim of this research is to make an up-to-date picture about the distribution of DS people.

A meta-analysis was performed in pubmed by the keywords: Down Syndrome, epidemiology, ratio, newborn, prevalence, mortality. Moreover we analysed the data of the European of Congenital Anomalies and Twins (EUROCAT) and the data of the International Clearinghouse for Birth Defect Monitoring System (ICBDMS).

The newborn ratio is correlated with the laws and the customs about abortion: for example in Ireland and in United Arab Emirates the prevalence of DS is higher than in France. Moreover the choice of abortion is different around the world: in Australia the ratio of abortion is lower than in USA.

In the period 2001-2005, the ratio of newborn with DS in Europe was between 3:10,000 and 26:10,000. The trend of this ratio was decreasing or constant during the time because of the recourse to abortion, only in Canada the trend is creasing.

Also the risk of a DS pregnancy changes with race: infants of Hispanic mothers, compared with infants of non-Hispanic white mothers, had a significantly higher birth prevalence of DS.

It is very important that every countries create a registry for controlling the prevalence of DS people in order to give them the suitable resources and structures.

Genetics

Oxidative Stress And Immune Dysfunction In Down Syndrome

Professor Aishah Adam (1), M Mahamood (1), MH Hasan (1), C Sunggip (1), M Ali Mukhti (1), NA Hamid (2), WZ Wan Ngah (2). 1. Faculty Of Pharmacy, Universiti Teknologi MARA, 40450 Shah Alam, Selangor; MALAYSIA

P34

The Cu-Zn superoxide dismutase (SOD) gene is present on chromosome 21, thus, individuals with trisomy 21 (Down Syndrome, DS) may be under oxidative stress.

The aims of this study were to determine the antioxidant and immune status in DS.

Blood was collected with informed consent from the parents or guardians of DS participants (153) and from age-matched controls (153). Activities of erythrocytic SOD, catalase and Se-glutathione peroxidase (Se-GPx) were measured using established techniques. Peripheral blood lymphocyte population was evaluated by flowcytometry. DNA damage was estimated by the comet assay. Plasma vitamin E was measured by HPLC.

SOD and Se-GPx activities were significantly higher in DS than in controls although catalase activities of both groups were similar. CD19+ levels were significantly lower while CD8+ levels were higher in DS persons aged between 1 to 30 than in age-matched controls. CD4+ levels were only lower in DS persons between 21 to 30 years than in controls. The CD4+/CD8+ ratios for DS individuals aged between 1 to 30 years were lower than in controls. CD56+ levels were lower in DS persons of 8 to 20 years than in controls. All DS persons showed more DNA damage than controls. No significant differences were seen in the plasma vitamin E levels of DS persons compared to controls.

In summary, DS persons experienced elevated antioxidant enzyme activities and a depressed immune status, indicating the presence of oxidative stress. They had more DNA damage than controls although their plasma vitamin E levels were unchanged.

Relationship Of Antioxidant-Oxidative Stress Status And Immune Function In Down Syndrome

MH Hasan (1), M Mahamood (1), C Sunggip (1), M Ali Mukhti (1), Na Hamid (2), WZ Wan Ngah (2), Aishah Adam (1), Universiti Teknologi MARA, MALAYSIA

P35

It is well established that oxidative stress status is associated with individual's immune status.

The aim of this study was to understand the involvement of oxidative stress in Down Syndrome (DS) by determining the antioxidant-oxidative stress status and the

immune function of these individuals.

This was a cross-sectional study carried out with informed consent on DS persons and age-matched controls from several locations in Malaysia. Antioxidant-oxidative stress status was assessed from measurement of antioxidant enzyme activities in erythrocytes, viz, SOD, catalase (CAT) and Se-glutathion peroxidase (GPx). Immune function was assessed from measurements of the main lymphocyte populations using flowcytometry and through determination of cytokines using Elisa kits.

GPx was shown as the most important antioxidant enzyme in modulating the number of most lymphocyte subpopulations and most likely has a protective effect to immune cells which included lymphocytes, T helper lymphocytes, B lymphocytes and NK cells. Unfortunately, this study failed to prove the association between IL-2, IL-6 and TGF-ß1 with antioxidant enzymes levels.

With respect to the association of cellular immune functions and antioxidant-oxidative stress status, these present results showed the related relationship between antioxidant enzymes and immune cells in DS persons and age-matched controls.

Assessment Of The Paraoxonase And Arylesterase Activity Pon1 In Dependance On 55(L/M) And 192(Q/R) Dna Polymorphism In Adult Patients With Down Syndrome

Ms Pavel Sykora, SLOVAKIA

P36

The aim of my study was to assess the paraoxonase and arylesterase activity of paraoxonase 1 (PON1) in adult patients with Down syndrome

Adults with Down syndrome (10 men and 10 women aged 16 to 37 years) participated and were compared with a control group (mostly brothers and sisters of patients with Down syndrome) (10 men and 10 women age range 17 to 45 years). I investigated the 55(L/M) and 192(Q/R) DNA polymorphism in every patient, by PCR-RFLP method.

The results show, that mainly the paraoxonase activity is either significantly (PON1 genotype LL/RR and LL/QR; p=0.019, fig 1) or non-significantly decreased (PON1 genotype LM/QR, LM/QQ and MM/QQ, fig 2) in patients with Down syndrome.

Education

Comparative Study Of The Social Activities, Participation And Friendships Of Irish Adolescents With Down Syndrome, Attending Mainstream And Special Schools

Loraine Matthews, Dr. Shay Caffrey, School of Psychology, University of Dublin, Trinity College Dublin, IRELAND

P37

Introduction: Research has found no difference in social inclusion or community involvement for adolescents with Down syndrome attending mainstream compared to those attending special schools. Social activities and recreation can encourage independence through links to perceived freedom, and has also been shown to improve social skills and help form relationships that can have lifelong implications.

Aim: This study aimed to explore if the type of school a child with Down syndrome attended, mainstream or special school, impacted on the quantity and range of social activities, leisure participation and friendships experienced by them as adolescents.

Method: 147 questionnaires were sent to families of adolescents with Down syndrome aged 12 to 19 years in both mainstream and special schools.

Results: The majority of daily activities were passive and home based. Clubs and swimming were the most popular weekly activity. The teenagers chose social activities 46% of the time. Family members were the most frequent companion overall. The special school group was more likely to have a family member as a companion during social activities. The mainstream group was significantly more likely to have a non disabled friend but these friendships did not extend outside school. Local community friends were seen by very few adolescents on a daily/weekly basis. The barriers most reported to social participation were not having friends to go with, and not knowing how to do an activity. Over 50% of the adolescents needed a 'little help" during all types of activities they engaged in.

Conclusion: Better supports for social integration and friendship development are required in all schools for adolescents with DS.

Development Of Tools For Assistance To The Formulation And The Implementation Of The Life Project Of Persons With Down Syndrome

Haelewyck M-C[2], Champeaux J-P[3], Bara M[2], Sanchez-Leighton V[3]. Institution(S) [2]Service D'orthopédagogie Clinique De L'université De Mons-Hainaut, [3]Trisomie 21 France, BELGIUM

P38

In France, the law of 2005 on the chance and equal rights, the participation and the citizenship of the people with handicap challenges us on the way in which we can support these people so that they can express their life plan and set up it themselves.

The objective is to carry out a research of which the goal is to support the accompaniment of the formulation and the implementation of the life plan of the people with Down syndrome by the development of methodological tools.

Through semi-directing interviews, of a recension of tools for evaluation and of a review of the literature, we highlight:

1. Essential resources (available or not) compared to the process of development of the life plan and self-determination,

2. Prospects for intervention (used or not),

3. Evolution of the tools for evaluation which consider self-determination, quality of life compared to the fields of life in which a person can show self- determined behaviors.

At the end of this, three types of documents will be produced:

- a guide intended for expression of the projects of the person by the person;
- a guide for the professionals supporting self-determination in the development of the life project
- a comparative analysis of the existing tools for evaluation of self-determination, participation and quality of life in term of populations, contexts, strengths, difficulties,…

We will expose the state of advanced research and the working recommendations to be followed.

School Inclusion Of Children With Down Syndrome In School Of All

Anna Lastella, Italian Down Syndrome Association, ITALY

P39

In Italy school inclusion of children with special needs has been effective since more than 30 years and Italian Down Syndrome Association (AIPD) has always been involved in its support. Specifically, the School Observatory (one of the Services of

the National Section of AIPD) offers a counselling service for families and schools, and courses for teachers. In 2000, the Observatory conducted a research on the quality indicators of school inclusion of people with Down Syndrome.

Our aim is promoting the maximum development as possible about cognitive, social and affective areas for people with Down Syndrome.

We found out as points of strength: team teaching with the presence of a special education teacher (assigned as a support to the class where the child with Down Syndrome is included), small number of pupils for each class, planning of goals and shared inclusion strategies (network).

Our data show that: early inclusion in the nursery and in the infant-school is important for children's psycho-motor and socio-cognitive development; the years of primary-school and the 1st grade of secondary school allow almost all the boys and girls to acquire basic school competences (reading, writing, arithmetic), these years are also really important for the social and affective growth; the 2nd grade of Secondary school allows the strengthening of social capacities and the development of individualized teaching programming (alternating school with job experiences). This double education is the basis for the following individualized professional training, oriented to the inclusion in the job world.

Finally, our experience shows that all the people with Down Syndrome can and should follow an individualized educational programming based on effective inclusion strategies in the mainstream school.

Ignoring Distractions: A Study Of Visual Attention In Adolescents And Adults With Down Syndrome

Dawkins, T. (Mcgill U), Landry, O. (U Of Western Ontario), Flanagan, T. (Mcgill U), Brodeur, D. (Acadia U), Flores, H. (Mcgill U), Burack, & J. A. (Mcgill U), Mcgill University, CANADA

P40

Our senses are bombarded by an abundance of information necessitating the ability to focus one's attention on the most relevant information and ignore distractions.

To compare the ability to ignore distractions among a group of typically developing (TD) children and persons with Down syndrome (DS).

Participants were asked to focus on the centre of a computer screen and identify which of two targets were presented. The target appeared with flankers presented to the left and right along the same horizontal plane. The proximity of targets and flankers varied to assess the ability to optimally narrow one's focus. Flankers were presented before, at the same time as, or after the presentation of the target to assess issues of attentional control in a real-world context where attention must be maintained within a changing environment.

Twenty persons with DS (10-28 years) and 58 TD children (5-12 years) were tested. Response times were significantly faster in the group with DS when flankers were presented further from the target. Persons with DS responded faster than the TD children when flankers were presented prior to and simultaneous with the target. Both groups were disrupted by the presentation of flankers after the target.

The ability to focus attention among persons with DS appears to develop along a typical developmental pathway. Persons with DS will benefit from eye-catching signals that draw their attention to important information. Once focused on a task, persons with DS are easily distracted by signals that are not relevant to what they are doing.

Multiple-Choice Tests With Corrections Allowed For People With Down Syndrome And Autism

Monari Martinez E., Department of Pure and Applied Mathematics, University of Padua, Padova, ITALY

P41

The valuation of academic achievements in students with severe language impairment may be problematic if, in addition, they have difficulties in sustaining attention, in writing and in other praxic skills, and if they have behavioural problems. In people with autism who are non verbal, for instance, all of these difficulties may occur together. Multiple-choice tests offer the advantage that simple praxic skills are required, allowing the tasks to be performed without physical support. Even so, attentive and behavioural difficulties may be so disruptive that achievements may be underestimated. Since teachers can give immediate feedback on each answer in these tests, a strategy might be to permit the student to correct their answers, and make further attempts, in order to mitigate these problems and to better capture their knowledge. This strategy can be applied even to tests of spelling and mathematical skills, where students are required to stamp the answers selecting from either 26 letters or 10 Arabic digits. A Microsoft Excel applet was designed to compute the statistical significance and the final grade of multiple-choice tests, as applied to tests of writing and mathematical skills, if up to two corrections per selection are allowed. The method, used with a nonverbal student with severe autism and Down syndrome, attending a mainstream secondary school in Italy, was useful, revealing his strengths, his weaknesses and his preferences, and allowed the teachers to grade his academic achievements effectively.

Investigating The Early Reading Abilities Of Children With Down Syndrome

Anne Van Bysterveldt, Gail Gillon & Susan Foster Cohen, University of Canterbury, NZ

P42

Currently there is limited research into the reading performance of New Zealand children with Down syndrome (DS) and the practices that facilitate its development. To begin to address this issue an examination was undertaken into the literacy skills of primary school aged children with DS.

To investigate the letter knowledge, real word decoding and phonological awareness abilities of 77 New Zealand primary school children with DS aged between 5;8 (y;m) and 14;11.

Children were originally recruited to participate in a wider study exploring literacy in New Zealand children with DS. The children's class teachers administered an assessment battery which included measures of letter knowledge, phonological awareness and real word decoding.

Participants were grouped by age into two groups; 5-8 years and 9-14 years. Participants were able to identify more letter names than sounds; however scores were not evenly distributed. Group scores were higher for the initial phoneme identity task than for the rhyme detection task, with more than twice as many children scoring above chance (using binomial test calculations) on the former measure. Twenty-four percent of all children were unable to read any words correctly and 6.6% were able to decode at a level expected for 7-8 year old children.

Preliminary findings suggest primary school children with DS demonstrate a wide range of letter knowledge, phonological awareness and decoding skills. Development of skills with maturation was evident. As a group, the older children achieved significantly higher scores than the younger aged group on all measures.

Inclusion Of Down Syndrome Persons In The National System Of Education: Reality And Desiderata

Ecaterina Gaidarji, Association of Rehabilitation and Social Integration of Children with Down Sindrome ARIS DOWN, Moldova, MULDOVA

P43

In the Republic of Moldova the inclusion of the persons with special needs into social systems is a new phase in the long and difficult process of integration. The Asociation Aris-Down Moldova started to make the first steps into this direction. Due to the multiple collaborations with the local and international NGOs, the exchange of experience during these collaborations, the cooperation with the state structures we managed to inform the society about the persons with DS through different possible ways: fliers, brochures, attending different meetings and even organizing a photo exhibition with and about DS people. The Asociation contains 280 families – all of which are members - all in all 500 people from Chisinau and other parts of the country. For about eight years we have worked with the kids, teens and their families in different programs, which were either part of the Asociation's programs or of the day care centre "Miracol", as follows: rehabilitation and social integration, education, personal autonomy and offering information and consultation for the parents. Our main goals are to diversify and multiply the materials and services offered by the Asociation, to create the conditions that would lead to the DS persons actually having a profession, to continue our work with the parents and include new topics in our classes with them, to provide the members of the staff with an exchange of experience, visiting other centers in the country and abroad.

Effects Of Regular Versus Special School Placement On Students With Down Syndrome - Review

Gert De Graaf (Dutch Down Syndrome Foundation; Department Of Orthopedagogics, University Of Gent, Belgium), Geert Van Hove (Department Of Orthopedagogics, University Of Gent, Belgium), Meindert Haveman (Department Of Rehabilitation Sciences, University Of Dortmund, NETHERLANDS

P44

Since the 1980's more and more children with Down syndrome are in regular education. Parents and schools expect social and cognitive advantages.

A review of studies since the 1980's on the effects of school placement of students with Down syndrome with special reference to self help skills, language, academics and social functioning is presented.

21 studies could be found in which a direct comparison was made between regularly and specially placed children. In addition, 7 studies were included in which the acceptance of regularly placed children with Down syndrome by their peers was evaluated.

Regular placement yields a better development of language and academic skills, even after the effect of selective placement has been taken into account. As regards self help skills, under the same condition, there seem to be no differences. For most social aspects (social network, behaviour, self competence) no differences at all or small positive differences for regularly placed children were found. However, although regularly placed children are generally fairly well accepted by their peers, they are less often seen as 'best' friend. Apparently, in special education there exist more opportunities for being 'best' friends.

Children with Down syndrome learn more academic and language skills in regular education, not only because of selective placement. They are well accepted by their peers. However, opportunities for the development of intimate 'best' friendships have to be organized explicitly.

"Mimocas Numbers" – Educational Software Designed To Promote The Mathematical Skills Of Children With Developmental Disabilities

Luísa Cotrim Psym, Teresa Condeço Psym, Miguel Palha MD, Jorge Constantino Engm, Portuguese Down Syndrome Association/Child Developmental Centre Differences, PORTUGAL

P45

"Mimocas Numbers" is an interactive software high in educational content, providing hours of entertainment in a play-and-learn environment while introducing the foundation skills in basic numeracy/mathematics. Skills are built on gradually and sequentially. This software program was designed for use with children with Down syndrome, aged 36 months and older.

1.To promote the development of mathematical language, comprehensive and expressive, by means of a visual learning process;

2.To promote number knowledge, number sense, number sequencing, numerals, numerical principles;

3.Introduces a new methodology based on visual processing and visual memory.

First Group– Pre-numerical skills (foundation skills): indefinite size and amount, quantity concepts (understand "how many"); size concepts; number sense; one to one correspondence; number identification; categorization; follow a pattern.

Second and Third Group – Work with numbers: 1 to 5 and 1 to 10 – number naming; quantity (How many?"); count forward and backward, understand one to one correspondence; understand the principles of addition and subtraction; build a "number ladder"; develops fast recall and mental calculation skills; automatic recall number of items; automatic recall represented number.

The "Mimocas Numbers" has been used in our daily activities since year 2000. This software is a powerful visual and interactive strategy. Over time we have seen an increased motivation to learn and a faster graft of the numerical principles.

The "Mimocas Games" is a successful strategy that allows children with Down Syndrome to access curriculum by promoting number knowledge and numerical principles.

Inclusion Of Students With Down Syndrome In Secondary Education. An Utopia Or A Real Possibility?

Sonja Uhlmann, Paula Martinelli, Down Syndrome Foundation Madrid, SPAIN

P46

Must all students with intellectual disability spend part of their academic life in a special school by the time they reach adolescence? Can these young subjects benefit from a curricular program in Secondary Education? Will they be able to acquire in such way the adaptative abilities that they will need in their adult life? Will the learning of a student with intellectual disability included in an ordinary school require a large amount of auxiliary resources to be sustained? These matters and many more have served us as a basis for a reflection about the reality of these youngsters with intellectual disability that we find in an inclusive education and who, due to the scarcity of programs adapted to their needs, must move to schools for Special Education .

In our presentation we wanted to show in a practical way how to manage inclusive education in secondary schools.

Our model has been introduced in one secondary school so far and will start at another two secondary school at September 2009.

With effective pedagogic proposals and an effective management of resources inclusive education at secondary levels is possible.

All Communication, All The Time: The DSRI Model And The Centrality Of Communication Teaching For Students With Down Syndrome

Andy Loebus, Down Syndrome Research Institute, CANADA

P47

The Down Syndrome Research Institute of London, Ontario, Canada (DSRI), was founded by the father of a child with Down Syndrome to address the educational needs of young people with Down syndrome that were not understood by the larger educational system. DSRI's mission is to investigate, implement and promote educational approaches that help individuals with Down syndrome experience success and independence at school, with friends, and in the world of work.

DSRI runs summer schools for preschool, elementary and high school-aged students. These summer schools are organized on a unique model, which places the communication learning needs of each student at the centre of the curriculum.

Many professionals work in the summer schools, but speech pathologists are at the heart of the DSRI model, and they have a large influence over what gets taught and how.

DSRI's research and parent reports indicate that students experience considerable growth in their ability to communicate during DSRI's month-long summer school sessions.

This presentation will explain DSRI's educational model, as well as DSRI's findings about optimal methodologies for students with Down syndrome.

Research Study- Speech And Language Therapy For Children With Down's Syndrome Phase 1: Systematic Literature Review And Consensus Statement

Baksi, L. & Colleagues, Symbol UK Ltd, UK

P48

This research project seeks to conduct exploratory work to identify, appraise and synthesise available studies evaluating speech and language therapy (SLT) for children with Down's syndrome and specialist speech and language therapists opinions about best practice.

This model of intervention differs from that usually provided through statutory funding in the UK: it provides more intensive speech and language therapy provision using specific intervention strategies that take into account knowledge about the communication and learning profile associated with the syndrome, while addressing individual's functional communication challenges.

This is the first phase of a more comprehensive project to assess the impact of targeted intervention for children with Down's syndrome.

The literature review will collate the available evidence on the different programmes of SLT used for children with Down's syndrome, and summarise their effectiveness with a view of providing directions for future research.

In parallel with the systematic review, the research team convened meetings of the SLT Specific Interest Group on Down's syndrome. This group generated a consensus statement on the speech, language and social aspects of SLT interventions.

Presentation of the consensus statement will outline the Group's views on intervention strategies to address speech intelligibility issues, language impairment and social communication skills, and eating and drinking issues, as well as service pathways.

A high level of consensus was found amongst speech and language therapists with specialist skills in working with people with Down's Syndrome, however these are not currently common practice in the UK.

Developmental Trajectories For Young Children With Down Syndrome

Angela Byrne, Michele Pettinato, Gillian Bird, Becky Baxter, Julie Hughes, Sue Buckley, Stephanie Bennett, Down Syndrome Educational International, UK

P49

A number of studies have shown that there is a particular Down syndrome behavioural phenotype; with relative strengths in social functioning and receptive language, and relative weaknesses in motor skills and expressive language. Little is known about how this behavioural profile emerges and develops over time.

To find out more about how this behavioural profile develops and changes over time in a group of young children with Down syndrome. To use this information to feed into timely early intervention programmes which focus on the specific learning needs associated with this behavioural phenotype.

2 Groups of young children (N= 40) aged 18-42 months with Down syndrome were assessed using Bayley III scale of infant and toddler development on Cognition, Receptive and Expressive Language, Fine and Gross Motor skills, and Social-Emotional Understanding (Time 1). Sixteen of the children were between 18-30 months and 24 of the children were between 30-42 months. They will be reassessed this year, 1 year from the original assessment date to see how their behavioural profile has changed over time (Time 2).

Behavioural phenotypes for children across 3 age ranges will be presented (M:24 months, M:36 months and M:48 months). In addition, profile comparisons will be made between the same children at Time 1 and Time 2.

Factors that influence early developmental trajectories in children with Down syndrome will be discussed. Practical implications for early intervention programmes and plans for future work will also be presented

Wellbeing For Children And Young People With Down Syndrome In New Zealand: A Conceptual Framework

Maree Kirk, Doctoral Candidate, Department Of Societies & Cultures, University Of Waikato, Hamilton, NZ

P50

Government and non government organisations measure the impact of welfare reform and social policies on children and their families through developing indicators of child wellbeing. A critique of social policy and a selection of national and international literature established the importance of wellbeing as critical to the social inclusion of children with a disability. There is an identified gap in current published literature on indicators of wellbeing for the specific population of children with a disability.

To explore the perception of wellbeing and the factors which influence it for students with Down Syndrome.

A qualitative study focused on student voice involving semi structured interviews, a range of interview support material as contextual references with primary focus on the student's use of photographs to record their perceptions of wellbeing in the school setting.

Thirty interview findings of what constitutes wellbeing are illustrated by the central themes analysed as participants' conceptual dimensions presented in a framework.

For students with Down Syndrome the factors which influence wellbeing are different. The ability to recognise the interrelatedness of these factors has a substantial influence on students. For professionals and service provision the understanding of these principles impacts on the student and their family to contribute to or inhibit the outcome of wellbeing and social inclusion.

Developing Advocacy Skills Through Group Work

Siobhan Mac Cobb, The Discipline of Occupational Therapy, IRELAND

P51

In order for people with learning disabilities to speak up for themselves, they need to learn the skills of advocacy. They also need to learn in the context of their daily lives, and to learn from each other as peers in asking, in listening to each other and in solving problems.

By working together in task focused groups , group memberships skills are learned that are the essence of peer advocacy skills.

The presentation describes a group process approach to the development of awareness of self, awareness of others and the devlopment of Listening Skills, Asking Skills, Giving Equal Chance Skills, Problem Solving Skills as part of an advocacy training course for service user adults with learning disabilities.

By applying group theory, and an occupation focus, a culture of advocacy is generated in this 18 hour / 9 session course.

Participants engage with each other in tasks to learn basic group memberships skills and advocacy actions. Learning is based on participants' daily experiences, and new advocacy actions are practiced and refined in daily life.

- People learn new advocacy skills, and act for themselves and for each other.
- Group work methods change the dynamics of service users relationships with each other and with staff.
- Staff recognise more opportunities for self advocacy and allow service users to speak up and solve their own problems.
- Peers offer solutions to daily life problems and offer support to each other, rather than over relying on staff.
- Advocacy training works if it is embedded in the day to day life of individuals with learning disabilities.
- Advocacy training is recommended for service users with learning disabilities as a way of ensuring safety and quality of life.
- There are opportunities for cultural change in staff and service agencies when providing and supporting advocacy.

Inclusive Education Maximising Resources

Rosalind Threadgold, IRELAND

P52

The revised primary school curriculum 1999, uses a child centred approach to education which is activity based. It incorporates an inclusive approach for children with special educational needs based on mixed ability groupings and incorporates creativity through the inclusion of drama and inter personal skills through S.P.H.E; (social personal, health and education) modules.

The purpose of the presentation is to outline effective teaching strategies that provide meaningful educational provisions for children who have Downs syndrome. The particular focus being; methods of curricular differentiation, the essential elements of the individual educational plan and child centred strategies; through the analysis of the N.C.S.E guidelines which were created to assist teachers in the implementation of the E.P.S.E.N Act, 2004 and from current Irish and International research.

The E.P.S.E.N Act, 2004 legislated that children with special educational needs should be educated where possible in their local school and placed the responsibility of their inclusion on the principle of the school, the board of management and the classroom teacher.

- Tools of inclusion
- Curricular differentiation
- Individual Educational Plan
- Whole school Plan
- Teaching strategies

It has been recognised since the S.E.R.C report 1991 that segregated education provisions inhibits the child with special needs from working, socialising and living within their communities and that Ireland was lagging behind International Best Practice of equality of opportunity for children as established by United Nations Convention of the Rights of the Child, 1989.

Karlstad Model

Margareta Hallner & Rigmor Bostrum, SV Studieforbundet Vuxenskolan, SWEDEN

P53

together with other parents, relatives, staff and other interested to learn more about the Karlstad model. The language training model from Karlstad has been in constant development since the late 1970's directed by Professor Irene Johansson and the research has been performed on children with Down's syndrome at different ages.

- to acquire knowledge about importance of working with structural language training for persons with Down's syndrome and their network.
- to meet and exchange experiences in seminars and courses to deepen knowledge about the Karlstad model. The gatherings also includes development and fabrication of own material that is adjusted to people with Down's syndrome.

Since 2004 participants of the seminars have learned more about language and speech so people with Down's syndrome can be participants in our society. New seminar leaders are trained every year to meet the increasing needs and demands.

- to start more seminars in language training to develop language together with others. The seminar meetings also create formal and informal groups that exchange experiences.

Phonological Awareness Of Children With Down Syndrome: Its Role In Learning To Read And The Effectiveness Of Related Interventions

Chris Lemons, PhD., School of Education, University of Pittsburgh, USA

P54

Phonological awareness (PA), the ability to hear and manipulate the smallest units of sound in our language, is key to learning to read for typically-developing children. Some have suggested that this is not true for children with Down syndrome (DS).

The purpose of this review was to determine whether individuals with DS perform more poorly on PA tasks than typically-developing peers and whether PA skills are related to current and future reading performance for individuals with DS. Additionally, the effectiveness of PA interventions for these individuals was examined.

First, studies in which authors evaluated relationships between PA and reading skills in individuals with DS were included. Second, studies were included in which children with DS participated in a PA intervention.

Results from a review of 20 studies indicate that individuals with DS perform significantly worse on PA tasks compared to typically-developing peers. However, statistically significant relationships between measures of PA and reading were found for individuals with DS. No study provided support for the claim that reading develops independently of PA among individuals with DS. Additionally, the review of

intervention studies provides evidence that PA interventions may increase explicitly taught PA and reading skills for some children with DS.

Evidence from this review supports the idea that PA plays a key role in learning to read for many children with DS. PA and phonics-based instruction may strengthen the reading of words not directly taught, comprehension, and fluency among children with DS. Implications for practice and future research will be discussed.

Auditory Instruction: A Third Option

Mr Cameron M. Bonertz, Brian K.V. Maraj, University of Alberta, CANADA

P55

The model of biological dissociation (Elliott et al., 1987) states that the verbal-motor deficit demonstrated by persons with Down syndrome (DS) is a function of a unique pattern of cerebral lateralization, namely, atypical left hemisphere lateralization of language combined with typical right hemisphere lateralization of movement production. Further, corroborating evidence has demonstrated that language is the only type of processing that is atypically lateralized. While auditory instruction has often been overlooked due to its association with speech, recent research (Ringenbach et al., 2006) has suggested that auditory instruction that is non-verbal in nature produces performance that is intermediate the visual-motor advantage and verbal-motor deficit.

The aims of this study are to confirm the intermediate performance of persons with DS in response to auditory instruction and to expand this result to motor learning.

Young adults with DS as well as typically developing participants matched for mental (MA) and chronological age (CA) performed a 3 step movement sequence in response to either visual (lights), verbal (spoken words), meaningful auditory (music), or non-meaningful auditory (tones) instruction. Reaction time and movement time data was recorded during acquisition trials in all four conditions and during retention trials following a 1-hour rest interval.

Preliminary results support the hypothesis that auditory instruction results in a pattern of motor performance and learning that is inferior to visual instruction but superior to verbal.

While meaningful auditory instruction is not as beneficial as visual, it is a more productive, and potentially viable, alternative to verbal instruction.

A New Zealand Resource To Support Successful Inclusive Transition Of Children With Down Syndrome Into Daycare And School

Mrs Zandra Vaccarino, New Zealand Down Syndrome Association, NZ

P56

The New Zealand Government's education policy is inclusive and parents with children with special needs have legal rights to access inclusive education. However, many parents find the process to access support for inclusive education traumatic because of the disparity between policy and actual practice and the complexity of the process. As a result, the transition process appears to be a catalyst for revisiting the grief cycle. Educators also need support in their initial engagement in the transition process.

To develop a resource to inform and empower parents on the transition process so that they can access inclusive education for their children entering school.

Key stakeholders were interviewed to provide an overview of government policy regarding the education of children with special needs, and families and educators were interviewed to share their stories and experiences regarding the transition process and inclusive education in order to produce a DVD.

The interviews were edited and an 88-minute DVD consisting of six sections was produced. Existing supporting resources were sourced from other organisations in New Zealand and included in a "transition-to-school" pack which was distributed.

Parents need support when navigating the journey to inclusive education. This resource pack provides parents and educators with answers to some of the who, what, where and how questions regarding the transition to inclusive education in New Zealand. This resource pack provides parents with information which empowers them to make informed choices regarding education for their child with Down syndrome, and acknowledges and addresses the emotional issues around this significant milestone.

Mental Wellness

Lifestyle Of People With Down Syndrome In The South Region Of Brazil

Marques, AC; Gaya, ACA; Bergmann, G. - UFPel - UFRGS - ULBRA, Federal University of Pelotas, BRAZIL

P57

In education perspective for an active lifestyle, the adherence to physical activity practice is considered an important health behavior for the comprehension of phenomena related with the implementation of health promotion programs for people with Down Syndrome (DS).

This study has objective to describe the characteristics and life habits of the population with DS aged seven years-old or more in the South region of Brazil.

This research is characterized as a cross-sectional epidemiologic study. A total of 2187 individuals were studied (54.7% men), with ages between seven and 64 years.

It was observed that 39% (n=852) of the individuals related some associated illness. It was verified that 12.5% (n=242) of the individuals are able to read and write. It was observed good autonomy in the accomplishment of the activities of daily life (ADL), around 90%, whereas the instrumental activities of daily life (IADL) are carried out with more difficulty. In relation to leisure activities, 45.3% (n=908) have preference for watching television. It was observed that 13.5% (n=296) use computers. In terms of physical activity practice, 65.8% (n=1482) are physically inactive. In the physical fitness and somatic evaluation, 1249 children and youth with DS of ages between 10 and 20 years were studied (53.6% males). In terms of BMI, it was verified that 56.9% are in the overweight or obesity categories, with more risk in girls.

Preventive actions will help handling the relative factors for activities and social programs, that can facilitate and promote the acquisition of healthy habits, stimulating and associative and happy life, that includes recreation, physical and cultural activities.

Speech and Language

Association Between Mouth Breathing And Tongue Protrusion In Children With Down Syndrome

López-Pérez Rubén, CD, MO; López-Morales Patricia, CD; Borges-Yáñez S. Aída, CD, MPH, DO; De La Fuente-Hernández Javier, CD, M. Universidad Nacional Autónoma de México, MEXICO

P58

AMSJB LMR ?RRCLB

be due to allergies, common colds or hypertrophy of the adenoids or the tonsils. However, they also present a disproportionate lingual musculature compared to the size of the oral cavity, for what many of them maintain the mouth open and project

the tongue outside of the same one.

To determine if the presence of tongue protrusion was associated with the presence of mouth breathing in a sample of Mexican children with DS.

AMSJB LMR ?RRCLB

presence of tongue protrusion was established when a boy or a girl was examined laterally, and the border of his/her tongue surpassed the contour of one or two of his/her lips during five different moments (when resting, sucking, drinking, swallowing, or speaking). Oral mouth breathing was diagnosed when an oral mirror was placed in front of the mouth for 5 seconds, and the mirror became misty. The X2 test was used to identify associations.

Forty one (71.9%) children breathed through the mouth and 46 (80.7%) presented tongue protrusion. A significant association between mouth breathing and tongue protrusion was found only when speaking [$X2 = 4.922$; $p < 0.05$].

In the studied sample, an association was observed among the habit of mouth breathing and projecting the tongue outside of the mouth when speaking.

Investigating The Effectiveness Of Integrated Phonological Awareness Intervention For Children With Down Syndrome

Anne Van Bysterveldt, Gail Gillon & Susan Foster-Cohen, University of Canterbury, NZ

P59

Individuals with Down syndrome (DS) experience difficulties with both spoken and written language development however controlled interventions studies to address these difficulties are rare and have typically focused on improving only one language domain.

To investigate the impact of an integrated phonological awareness intervention on the speech, phonological awareness and early literacy development of pre-school children with DS immediately post-intervention and after 2 terms of formal schooling.

Participants were ten pre-school children with DS aged 4;4 (y;m) to 5;5 attending an early intervention centre. The experimental intervention involved a collaborative approach between the children's parents, computer specialist and speech-language therapist (SLT). The computer specialist and SLT each implemented an activities based component with the children individually for 20 minutes weekly for a 12 week period (i.e., 8 hours total) and the parents implemented a print referencing component during joint story reading four times weekly during the course of the intervention (approximately 12 hours total). Children were assessed on measures of speech, phonological awareness and early literacy, at pre- and post-intervention and after 2 terms of schooling.

All participants made significant gains on speech measures post-intervention and nine made continued gains at follow-up. Participants showed increased awareness of letter knowledge and initial phonemes in words. At age 6-7, five children showed evidence of transfer to real word decoding and three to real word spelling.

Results provide evidence in support of this collaborative intervention to simultaneously facilitate speech sound development, letter knowledge and phoneme awareness skills in young children with DS.

Unique And Intense: A Model For Speech Language Pathology Service Delivery And Teaching Of Communication For Students With Down Syndrome

Jennifer Shields, Down Syndrome Research Institute, CANADA

P60

The Down Syndrome Research Institute is an organization based in London, Ontario, Canada that takes a multi-pronged approach to working with young people with Down syndrome. The Down Syndrome Research Institute runs summer schools, organizes homework clubs, cooperates in research on educational issues pertaining to Down syndrome and educates teachers about educational approaches that are successful with young people with Down syndrome.

DSRI summer schools operate under two foundational principles. The first principle is that since communicative ability is so closely tied to quality of life for individuals with Down syndrome, the development of students' communication is the overarching aim of all instruction. The second foundational principle of DSRI is that DSRI team members collaborate closely to achieve the educational and communication goals that are selected for each child.

The unique and intense model of speech pathology service delivery and communication teaching invented for DSRI involves multiple modes of service clustered around a daily "Systems" programme.

Visitors to DSRI summer schools have expressed surprise at the intensity of the work. Along with their students, Speech Language Pathologists, teachers and others work in non-standard ways, confounding traditional professional role expectations.

This presentation will discuss the special features of the speech language pathology programme in the DSRI elementary summer school programme, and indicate some directions that may be pursued in the future.

Vocabulary Development In Italian Children With Down Syndrome

Zampini, L. & D'odorico, L., University of Milano-Bicocca, ITALY

P61

Although different studies underlined how lexical abilities are quite preserved in children with Down syndrome (Vicari, Caselli & Tonucci, 2000), normative data on vocabulary size of Italian children with this syndrome are not available.

The principal aim of the present study is to assess vocabulary size and its relationships with chronological and developmental age in children with Down syndrome.

Vocabulary development has been assessed by the administration of the Italian version of the MacArthur Communicative Development Inventories (Caselli & Casadio, 1995). An amount of 152 questionnaires has been collected from parents of children with Down syndrome aged two to five years.

Data analyses show that word production and word comprehension are more correlated to developmental age than to chronological age.

Dividing the sample into groups on the basis of developmental age, word production at 12 months does not appear significantly different from normative data on typically developing children, while vocabulary size at 18 and 24 months is significantly lower in children with Down syndrome.

Moreover, a significant relationship has been found between the spontaneous word production during free-play sessions and data indirectly collected by the questionnaire.

In spite of a wide individual variability, lexical development in children with Down syndrome seems to lag behind cognitive development.

The positive correlation found between the spontaneous word production and the vocabulary production indirectly evaluated emphasizes the validity of the Italian version of the MacArthur CDI as a measure of lexical development in children with Down syndrome.

Karlstadmodellen - Johansson Language Methods

Ms Jeanette Persson, Jan-Olof Andersson, Susanne Einarsson, SWEDEN

P62

We are a family with a daughter, 8 years old in 2009, we have worked with Karlstadmodellen since she was newborn and still today in school we continue during her speaking, reading and writing development.

We are parents and also our daughters assistant from school will talk about her work with Karlstadmodellen in school.

You need to try different ways of learning and people with DS have also a possibility to learn both reading and writing, but you need a good structure and correct material and tools.

To show how you can work with Johansson Language Methods - Karlstadmodellen from early beginning and continue during many years of the child/youth/adult.

To show how you can make a combination with both parents/siblings and pre-school/school.

Today we are working in network and we can see the result of that everyone around our daughter works in the same way, with the same focus areas.

We work at home in our way and in school in another way but still we have the same goal.

With Johansson language methods we work with sign language, pictures and of course the normal speech. This in a combination is good for children with DS. This because children with DS needs a lot of inputs to learn the language.

Also that Karlstadmodellen believes in the human being and the every person belongs to the society.

Study To Evaluate The Efficacy Of The Listening Programme In Improving Auditory Skills And Speech For Children With Down Syndrome

Jeyes G.A. & Newton C., UK

P63

Individuals drawn from members of the Down Syndrome support group, Nottingham joined in this study to see if improvements could be made in the area of auditory processing and language development for their children.

This pilot study was to trial tests and questionnaires for suitability for use with children from the age of five, and establish if there was any benefit in children with Down Syndrome using The Listening Training Programme.

Individuals aged between five and fifteen years, were tested pre -intervention using Naglieri Non verbal cognitive ability test, TAPs forward digit span , Celf receptive and Expressive language, Rhythm test (Dilys Treharne Sheffield), mispronunciation detection test (Maggie Vance- Sheffield) and Renfrew word Finding test. After testing the children listened to modified classical music for half an hour per day, 5 days a week, over the 12 week period of The Listening training Programme and were then retested. Intervention took place in school or home. Questionnaires were completed by parents and teachers involved.

Most children were unable to complete the standardised tests. Their attention span and comprehension of test requirements proved to be a difficulty. Those who were able to do the mispronunciation detection test, showed improvement. Teacher's and parent's questionnaires universally reported greater usage of words, better listening and attention, greater clarity of sounds at beginning and ends of words.

Knowing specific areas that were improved appropriate tests could be used to substantiate this in a formal study involving a wider population.

"Sign Language Workshop": A Communication Support Program To Promote Early Communicative Skills In Children With Developmental Disabilities

Luísa Cotrim PsyM, Teresa Condeço PsyM, Sofia Macedo PsyM, Miguel Palha MD, Fernando Ramos PhD, Margarida Almeida PhD, Portuguese Down Syndrome Association/Child Developmental Centre Differences, PORTUGAL

P64

The children with Down's syndrome could present development disorders and language impairment, especially in speech development in the pre-verbal phase. Some studies suggest, thus, that the early signing period can be a bridge from the pre-verbal phase of communication to spoken language.

The "Sign Language Workshop" is an interactive multimedia application that offers a wide range of examples and suggestions of natural and eventually symbolic gestures, intended to:

- be an essential support for parents and therapists working with children

The "Sign Language Workshop" was designed as an extended communication support program for parents, educators and therapists of children with difficulties with speech sound production.

Children with developmental disabilities must understand basic elements of communication, such as turn taking, joint attending and the role of other people as communication partners.

The natural gesture may be used to: enhance prelinguist interactions and early pragmatic skills; enhance parent-child interactions; facilitate expressive vocabulary acquisition (with and in the absence of speech).

The development of this software to promote early communication abilities is framed on a methodological process that privileges not only the specification and conception of a multimedia application, but mainly, the adjustment of the application to the individual, social and contextual specificities of it target audience.

Communication At Work

Ally Attwell & Debbie Rickard, Voice Thru Your Hands Charitable Trust, NZ

P65

Voice Thru Your Hands Charitable Trust is dedicated to raising awareness of the importance of New Zealand Sign Language(NZSL) for children with Down syndrome. Children that are not given the opportunity to express themselves are being robbed of their rights as human beings.

The aim of this workshop is to remove the barriers that many children with Down syndrome encounter due to problems with verbal language. Communication is the key to participating in society. Therefore, every child, whether they are deaf, hearing impaired or non-verbal, has the right to have a voice. Through sign language children are given the opportunity to communicate and fully express themselves.

New Zealand has adopted NZSL as its third official language. From a parent's perspective this workshop will highlight how Tarryn has overcome the barriers of communicating by learning NZSL. Disability is in society not in Tarryn - if everyone knew sign language there would be no barrier for her.

Come and meet Tarryn and see first-hand how this little 9 year old has become a strong advocate for communication.

Participants will be empowered to understand the importance of communicating through sign by being introduced to the language and how it links with Deaf culture.

The Voice Thru Your Hands Charitable Trust was set up as we believe there is a gap in our children's language learning. Our mission is to raise awareness of the importance of NZSL and to show through communication in NZSL, people are able to fully express themselves.

Chatter Challenge

Eckert M., Pym G., Down Syndrome Society of South Australia, AUSTRALIA

P66

This project was sponsored by the Telstra Foundation. The aim was to design as specialist speech and language resource kit for parents and early intervention personnel that would assist them to promote the speech and language skills of babies, infants, toddlers and preschoolers with Down syndrome.

In order to produce such a program the following areas were researched and relevant data collected and documented with supporting photographs and video: Oral motor stimulation; Feeding; Auditory stimulation; Early attending skills; Social language skills; Receptive language skills; Speech development; Expressive language and signing vocabulary. The programme involved 60 children.

This resource kit is user friendly, developmentally sound and sequential, self evaluating, and underpinned by behaviour support principles. We have amalgamated best practice from a number of sources. Parents and professionals are able to work through the programme at the child's individual rate, and in a responsive and needs-based manner.

The project has produced a Resource Kit that includes:- A User's Guide; A comprehensive range of parent information handouts; A wide range of activities/ games to promote speech and language development; Extensive use of photos to assist the user's understanding; Fridge Cue Cards which include early signs and categories including - body parts, toys, etc. Sets of sound cards for individual speech sound practice; Troubleshooting Section.

Building A Young Child's Language Skills Without Pain And Suffering

Ms Mary Frances Edwards & Ms Diane Lowry, Kerry Branch, Down Syndrome Ireland, IRELAND

P67

Parents are frequently overwhelmed with the amount of practice and drill requested by speech-language therapists and early intervention specialists. They feel responsible for much of the communication progress expected from their child but find that life intervenes - they are unable to set aside the recommended amount of "work" time and thus feel guilty and inadequate. (Participants may like to pair this presentation with the presentation Toys for Language Stimulation which follows).

This presentation will provide specific strategies for developing language skills which are fun and easily implemented in everyday activities. Participants will obtain ideas for stimulating communication skills without hight expectations of extra time commitment.

Ideas for incorporating good language modeling practices into play and daily activities will be provided. In addition, there will be specific strategies that are especially stimulating for improved language. A set of communicative temptations will be explained and demonstrated, as will several methods of indirect language stimulation.

Participants will have an understanding of how to make stimulating language development fun and painless - a part of daily living. They will understand how communication development is more than just developing the first word.

Parents and educators can be excellent language teachers in the natural environment and can feel confident in using the techniques provided.

Structuring A Social Communication Group For Young Adults With DS

Ms Diane Lowry & Ms Caitriona Ryan, Speech & Language Therapists For DS Ireland, Cork branch, IRELAND

P68

Young adults with Down syndrome are reluctant to enter into social communication and/or interactions in community based settings due to a lack of familiarity with a variety of environments and social situations. The need for structured introductions into social environments is necessary so that appropriate communication skills can be accomplished. By providing young adults with Down syndrome with opportunities to practice these skills they will become more self confidence and independently venture out to these settings.

This presentation will demonstrate how the structure of a social communication group for young adults with Down syndrome can enhance a variety of communication skills for community utilization.

A group of 8 young adults from the DSI Cork branch participated in a social communication group meeting that discussed an upcoming community outing. The meeting focused on preparing the adults with vocabulary, language pragmatics and social skills pertinent to the community outing. The outing was then scheduled for the following week where practical application was completed.

The results of these outings and the adults' participation skills will be shared with the audience. Specific check lists of skills taught and mastered will be discussed. Measurement outcomes will be presented.

Providing young adults with Down syndrome a safe and structured environment to practice social communication skills can provide a great benefit. With this understanding, educators and parents can begin to create opportunities that simulate real life situations.

Toys That Stimulate Language

Ms Diane Lowry & Ms Mary Frances Edwards, Speech & Language Therapists With DSI Cork & Kerry Branches, IRELAND

P69

Parents of children with Down Syndrome resulting in significant communication difficulties often feel their child is not learning language if the child does not speak orally to communicate. Parents need to be aware that there is more to language than talking out loud. Language can be learned more naturally in real-time daily activities than in a structured "work" session. Receptive language skills and basic cognitive skills pave the way for oral communication. These skills, as well as the much desired 'first word' are best facilitated through a young child's play. Play is a child's work; it is important to the development of early communication skills!

This presentation will provide practical ideas for using toys to stimulate speech and language development. By using early childhood toys, parents can give their child the rich language stimulation needed for good communication skills in the midst of living life normally.

A variety of toys, as well as household items, will be presented and play opportunities with them demonstrated. Parents will have the opportunity to try their play techniques in the session.

Attendees will leave the presentation with a clear sense of how to 'do' language stimulation with a variety of toys and household objects. The participants will generate lists of language skills that each toy stimulated to take home as a memory aid.

Parents will feel empowered once they learn how to use common toys and household objects to stimulate language development during every day activities.

Quality of Life

Trying To Get Over Prejudice On Down Syndrome

Hasegawa T (Medical Advisory Board) & Takemura K (In Charge Of International Information Bureau, PAO), Japan Down Syndrome Society, JAPAN

P70

Down syndrome is no more than one of chromosomal abnormalities and just one of variations in humans. However, features of Down syndrome are sometimes regarded as much more special than other congenital disorders. We suppose it is a biased view we must change, or they might be treated inappropriately in society.

Our aim is to get over prejudice against the persons with Down syndrome by reconsidering whether so called typical features they have are very special or not.

Observations of and conversations with the persons with Down syndrome, aged from 0 to 63, at several clinics, meetings, and at home. Some through Email.

Most of the typical features of Down syndrome can be explained by medical and psychological evidences, and not all of them are special disorders. For example, not-Asiatic appearance can be explained for their small maxilla. Stubbornness can be explained as a psychological reaction they show when they cannot understand situations and how they should act.

Our study suggested that Down syndrome is not so special, so will propose a hypothesis: the persons with Down syndrome just have three kinds of problems which have to be treated, but everything else might be normal. These are (1) muscle hypotonia, or loose joints, (2) developmental retardation and characteristic developmental patterns, such as dominant visual cognition, (3) variable complications which are also seen in general population.

We conclude that we should treat the persons with Down syndrome not as special peculiar subjects, but OUR common citizens.

Discrimination In Immigration - A Case Study In Strategy

Miss Catherine McAlpine, Down Syndrome Victoria, AUSTRALIA

P71

Down Syndrome Victoria in collaboration with the Down Syndrome Australia network of state based associations ran a strategic media campaign that resulted in the Australian Immigration Minister granting permanent residency to a family that included a member with Down syndrome and the creation of a national inquiry into disability and immigration.

The aim was to develop a strategy which allowed a small membership based organisation to bring the issue of discrimination in immigration to national and international attention.

Down Syndrome Victoria had previously developed a flexible, responsive and opportunistic community awareness strategy. The Down Syndrome Australia network had also established a communication tool and protocol that allowed fast response times.

Down Syndrome Victoria built on previous work by staff and members in the field of immigration to develop a national coordinated strategy to call on the Australian Government to not only approve the family's application but also to inquire into ongoing discrimination against people with a disability and their families in migration matters.

The case received considerable international and national media attention and generated considerable public support for both the family and the issue in general. After only six weeks, the Australian Immigration Minister announced he would use his discretion to ensure the family was granted permanent residency. Together with the Parliamentary Secretary for Disability he also announced the Joint Standing Committee on Migration to inquire into the issue of the treatment of people with a disability in migration matters. This was a significant turnaround in a very short period of time.

A small member based organisation was able to influence national policy through a considered strategic approach.

The Healing Powers Of Journalling

Ms Erin Lane, North Island College Student Employee, CANADA

P72

This poster is about journalling to describe everyday life, experiences, feelings, thoughts and reactions while I am living them. My writing consists of capital, lowercase, different sizes, and words to describe the magnitude and power the word has for me. The pages are full of symbols, descriptions, codes, poetry and quotes. The different techniques help me to connect with life on a deeper, more intimate level. It

that writing, as much as possible in one day, has taught me, to discover meaning, and quiet in my life.

To demonstrate how journalling is important as it helps people to understand, trust, love and find peace with themselves. I would like to show others, that individuals with Down Syndrome should be given every opportunity to read and write.

I will show on my poster, how I have used journaling to track and process information, by recording my life in words. I will be on site to discuss my poster, with parents, teachers, and anyone interested in the topic.

Journalling has helped me find peace, understanding, beauty, love and happiness, in the small moments. Quite frankly, by writing, I have respect, more respect for myself, who I am, and why I do what I do, love with all my heart. I can now say, I have a best friend in me.

My poster will show the benefits of journalling.

- encourages creativity
- answer questions about the world and yourself
- helps to process information
- overcoming obstacales
- enhance memory

Katie's Excellent Adventure

Kathryn Edwards, Megan Brown, Katherine Wrenn, Institute for Applied Behavior Analysis, USA

P73

How do you change how others have labeled you when you've been called "the most severe, dangerous, stubborn, manipulative, attention-seeking, brat, the child who cried wolf too many times, and the girl who jumped in the swimming pool to be saved"? It's easier to show you than to tell you!

Katie, a woman with Down syndrome, is able to use her new life experiences and relationships to alter the stereotypes and preconceptions that had been associated with her ten-year history of institutional placement.

Katie will portray her epic journey from infamous to famous by sharing in pictures her connections with others, and her realization of many valued social roles following her return to her home community.

This photomontage will represent Katie's new roles as a: tenant, daughter, sister, teacher and advocate, and as a person happy to live an enviable life.

The inevitable conclusion of this journey in pictures is that Katie has shed the old labels and now embodies the socially valued roles that others aspire to.

Life Possibilities

My Life My Choice: I Am Proud Of Myself, And My Family Are Proud Of Me As A Person With Down's Syndrome

Dr Ghasem Norouzi, Isfahan University, School Of Educational Sciences & Psychology, Isfahan, Iran, Isfahan University, IRAN

P74

This paper discusses the findings of a life history of work, education and social life of Paul Savage who has Down's syndrome. Paul is 29 years old, the 2nd child in his family, and lives with his parents in NORTHTOWN in England.

Paul's life shows that how the family's attitude toward a child with learning difficulty is important to increase self-esteem and self-confidence and also to support the child to create a satisfying life.

Paul's life story, constructed from tape-recorded interviews, observation, filed notes, hand writing, social and school achievements records.

In this paper, Paul's story explored how a person with learning difficulties can be successful in the community. The story highlighted very important factors which supported Paul's ability to have a satisfying life: living in the community; having a supportive family; his parent's positive attitude toward Paul; having self-esteem, self-confidence and autonomy; having a positive attitude toward himself; receiving mainstream education with adequate support; contributing to and membership in the community, having social relationships with several people; learning a lot of skills and having opportunities to speak up in the self-advocacy group; having extensive leisure activities and aspirations in his life. In addition, the story indicated a number of difficulties facing Paul in his life: 'bullying' by other people; people's interference in Paul's life; lacking appropriate provision at college; lacking links between training and employment; lack of paid work and the vagaries of the benefit system.

The findings point towards a number of ways in which services can be improved for people with learning difficulties in the community: developing an appropriate curriculum, particularly suitable vocational training at college; making links between training and employment; providing a more flexible benefit system; increasing supported employment; providing mainstream education and employment.

Hearing / ENT

Otological Manifestations In People With Down Syndrome

Howard Savage Jones FRCS, Consultant Otolaryngologist, Midland Regional Hospital; Theresa Frawley MSc., Clinical Nurse Specialist/PhD student, MRHT & Trinity College Dublin, IRELAND

P75

We review the management of otological conditions arising in association with D.S

Method: A 30 year retrospective literature review of Index Medicus listed journals is interpreted in the context of regional service provision within the Republic of Ireland.

Results: External auditory meatal stenosis (EAMS) may cause conductive hearing loss and complicate grommet insertion/follow-up. Regular microaural toilette is required. Otitis externa however is not documented. Eustachian tube dysfunction provoking ventilation disturbance, glue ear, atelectasis and cholesteatoma is more frequent than in the general paediatric population and may continue into late teenage. Multiple re-insertions of grommets may be necessary but otorrhoea or rapid extrusion rate may prompt BAHA insertion.Tympanoplastic surgery is not well documented; EAMS and small mastoid air cell systems dictate canal wall down mastoid surgery for cholesteatoma management. Hearing loss affects 80%, 25% of these having sensorineural loss; however imaging studies suggest that most individuals have identifiable cochleovestibular abnormalities.

Precocious presbyacusis occurs in 20/30 age group; hearing aids fitting may be unsatisfactory due to EAMS, but BAHA technology has proven to be particularly well tolerated.

Hearing loss affects all age groups; premature presbyacusis is an increasing problem and justifies screening of the adult population. BAHA is the most beneficial advance in otological rehabilitation in 30 years.

Conclusions:There is a paucity of long term longitudinal studies and reported patient numbers are limited. The increasing age profile of the DS population will see greater numbers benefitting from the management of OSA and the development of BAHA technology and enhanced long term psychological management particularly in light of the precocious physical and psychological aging.

ENT Manifestations People With Down Syndrome

Howard Savage Jones FRCS, Consultant Otolaryngologist, Midland Regional Hospital, Theresa Frawley MSc., Clinical Nurse Specialist/PhD student, MRHT and Trinity College Dublin, IRELAND

P76

We review the management of ENT conditions arising in associations with D.S

A 30 year retrospective literature review of Index Medicus listed journals is interpreted within the context of regional service provision within the Republic of Ireland.

Results: The otological manifestations in D.S. may result in hearing changes in 80% of individuals, 25% of whom may have sensorineural hearing loss.

Ear canal stenosis requires regular microaural toilette , and may also compromise grommet insertion, follow-up maintenance and hearing aid provision.

Eustachian tube dysfunction necessitates active management with grommet insertion to correct hearing loss due to glue ear and may provide prophylaxis against the development of otitis media, retraction pockets, perforations and cholesteatoma.

Sensorineural hearing loss is recognised as having both congenital and acquired aetiologies; premature presbyacusis may become increasing prevalent due to the aging D.S. population.

Bone anchored hearing aids (BAHA) are particularly applicable to the problems associated with narrow ear canals, glue ear continuing into teenage and precocious presbyacusis.

Rhinosinusitis is exacerbated by structural and immunological factors, and whilst the development of functional endoscopic sinus surgery (FESS) has added an important perspective to the management of recurrent rhinosinusitis, more conservative topical and systemic pharmacology, irrigation and adenoidectomy still form the mainstay of therapy for the majority.

Laryngomalacia and age-relative subglottic narrowing are recognised but increasing awareness of obstructive sleep apnoea (OSA), its assessment and management has prompted an opinion favouring population screening.

Screening for atlanto-occipito-axial subluxation is also mooted and maybe particularly relevant in pre-op assessment prior to general anaesthesia and ENT surgery.

Conclusions: There is a paucity of long term longitudinal studies and reported patient numbers are limited. The increasing age profile of the DS population will see greater numbers benefitting from the management of OSA and the development of BAHA technology and enhanced long term psychological management particularly in light of the precocious physical and psychological aging.

Obstructive Sleep Apnoea Syndrome (Osas) In Children With Down Syndrome. An Assessment Of Prevalence And Symptom Frequency In An Outpatient Down Syndrome Population

I Hadjikoumi, H Wolfenden, C Tzivinikos, S Crowley, L Filby, S Jenkins, M McGowan, St George' s Hospital, UK

P77

The prevalence of OSAS in children with DS is 30-60%.

To determine the prevalence of OSAS in our paediatric DS population and to assess the frequency of symptoms among our patients.

Retrospective case note analysis of all outpatient attendees over a 25 month period, to identify those with documented symptoms or those with already diagnosed OSAS. A specially designed questionnaire was conducted via telephone to the parents of all attendees with no documented symptoms. Overnight pulse oximetry studies (POS) were subsequently performed for the group of children identified to have 3 or more symptoms (a cluster) from the questionnaire.

44 patients were followed up . The prevalence of one or more documented symptoms in our population was 34% (15/44). The prevalence of diagnosed OSAS was 16%, with all diagnosed patients reporting cluster of symptoms. From the group with no documented symptoms, 46% (11/24) of parents reported a cluster of symptoms during telephone questionnaire. POS were done in 7/11 of these children and found to be normal.

The prevalence of OSAS in our population is lower than previously reported in similar populations but a further 25% were found to have a cluster of symptoms . Parents of children with Down syndrome significantly underestimate the severity of their child's sleep disturbances, with poor correlation reported between symptoms and POS results. In children with DS a negative POS does not exclude OSAS.Our results may point to the need for objective screening for OSAS in children with DS.

Employment

Employment- Pathways Via Sport & Recreation

Ms Catherine McAlpine, Down Syndrome Victoria, AUSTRALIA

P78

An existing partnership between state based Down Syndrome Associations and the Australian Football League (AFL) offering sport and recreation opportunities to people with Down syndrome has been developed into a strategic initiative to create open employment outcomes within the Australian football industry.

Expand and develop existing initiatives offering one-off opportunities for people with Down syndrome to interact with AFL umpires to an integrated strategic approach to develop pathways to open employment.

Down Syndrome Victoria and the AFL Foundation developed a pilot program providing a sport and recreational opportunity with AFL umpires. The success of the initiative encouraged the AFL to expand Achieving Goals Actively nationally.

The partnership with the AFL also evolved into an opportunity for adults with Down syndrome to have a work experience placement assisting AFL umpires (Friday Night Footy). Both initiatives were well supported by members.

However, feedback indicated that the 'one-off' nature of these initiatives, while regarded as fun for the participants, did not result in any genuinely inclusive outcomes for people with Down syndrome. In respose, a strategy for meaningful employment outcomes was devised.

The pilot program is under development but indications are that a high proportion of the participants will achieve an employment outcome.

Sport and recreation is an excellent forum for contact between people with disabilities and those without. The relationships established in this environment break down barriers and encourage proactive identification of broader opportunities.

Not Just A "Job" Anymore: Career Opportunities For Adults With Down Syndrome

Dr Melissa L. Rowe, Down Syndrome of Louisville KY, USA

P79

While hiring people with disabilities is on the rise, the percentage of working individuals is still low (37% nationally) in comparison to non-disabled individuals (80%). This percentage is even lower in adults with intellectual disabilities (28%). When placed by a supportive employment agency, adults with Down syndrome (DS) are repeatedly employed in traditional jobs such as food service, department store or grocery positions. Our program, Career Solutions, takes a more progressive, individualized approach to supported employment for adults with DS.

The mission of Career Solutions is "to enhance employer's productivity, capital, and diversity by facilitating the placement of skilled individuals in valuable occupations". Using person-centered job selection, our program aims to find a career path for adults with DS based on their skills, interests, strengths/weaknesses, and personal goals. Benefits to both the employee with DS as well as the employer are considered.

Our person-centered employment approach as well as specific examples of individuals placed in successful employment through our program will be discussed. We will also examine how changes in supportive employment can be made in your own communities.

Career Solutions has proven to be an asset for businesses in our community by helping to find qualified, motivated employees who happen to have DS. We are currently serving 15 working adults with DS and continue to assist them long-term.

Not only is it intrinsically important for adults with DS to work, but as we will show, it makes good business sense to employee people with DS.

Aspects Of The Working Experience In People With Down Syndrome

Dr Eduardo Bilboa, Pontific Catholic University of Campinas, BRAZIL

P80

This research is about subjective aspects that result from the experience of inclusion of youngsters with Down Syndrome in the work market. It is done through the analysis of the reality of work of youngsters with Down Syndrome and the base of our research is Vygotsky's theoretical principles of Historic-Cultural Psychology based AMSJB LMR ?RRCLB the context where he develops himself. This article is part of a qualitative approach research and we use semi-structured interviews with the youngsters and their families (audio recorded). As results, it is expected that the analysis of the interviews may originate reflections about development and inclusion, and we also expect to demonstrate the importance of effective inclusion in the working market for the development of the youngster and, consequently, offer elements for actions that may promote more social justice.

Independent Living

The Israeli Down Syndrome Youth/ Graduates Movement

Rivka Sneh (The Israeli Down Syndrome Association) ISRAEL

P81

Introduction: For the first time in Israel a semi-independent movement of Down Syndrome "graduates" has recently been set up in full cooperation with the national Down Syndrome Association. There is full co-operation and affiliation with the national organization and the elected officers of this movement meet amongst themselves to discuss issues that pre-occupy them and also in order to make plans for future activities of their own national movement. This is the first organization of its kind in Israel organized by those with DS for themselves.

In March of this year (2009), the movement was "officially" founded at an impressive event where a manifesto was jointly written and democratic elections took place where a chairman, vice chairman, secretary etc were elected as were a wide variety of committee.

The Main Aims:

1. To increase involvement, partnership and responsibility in the decision making of the movement.
2. To strengthen the ties and affiliation with the national Down Syndrome Association.
3. To organize independent meetings and activities where important relevant subjects such as housing, employment, inclusion, free time and other relevant problems are discussed and possible desirable solutions are suggested.
4. To strengthen the social interaction between the members through all available means of communication especially an internal newsletter published four times a year.
5. Preparation for lobbying public figures on the subject of realizing the member's rights.

Methods: In our national Down Syndrome Association there are about 300 graduates above the age of 18, spread out all over the country and therefore we organized both regional and national activities.

Results:

The enormous enthusiasm was shown during and after the actual foundation activity of the new movement, where 60 youngsters from all over the country took part. This level of participation proves the necessity of this sort of organization.

Future Plans:

The committees are preparing activities for the annual national Down syndrome family conference and holiday, discussing the topics for their own activities and delegating responsibility to movement members who will act as auxiliary helpers with the younger children with Down syndrome.

We are hoping in the near future to make contact with similar groups in other countries.

Physical Activity

A Pilot Study To Investigate The Level Of Physical Activity In Adults With Down Syndrome

Nora Shields, Hannah Johnston, Catherine Warren, Karen Dodd, Dennis Wollersheim, La Trobe University, AUSTRALIA

P82

Adults with Down syndrome are recommended to engage in 30 minutes of moderate level physical activity every day to maintain good health. There are currently no data on the activity levels of adults with Down syndrome.

This pilot study aimed to (1) establish the feasibility of using accelerometers to measure physical activity in adults with Down syndrome and (2) determine if adults with Down syndrome met the recommended levels of physical activity.

10 adults with Down syndrome (2 women, 8 men; mean age 31.2 years, SD 10.3 years; mean BMI 32.3, SD = 9.1) wore tri-axial accelerometers (RT3) during waking hours for 7 consecutive days. The accelerometers measured the time spent by the participants in low, moderate or vigorous levels of activity each day.

Two adults were unable to tolerate wearing the accelerometer. Four participants met the recommendations for physical activity participation on at least 5 days of the week. The average amount of moderate activity undertaken per day was 36.5 mins (SD 23.9 mins). The average amount of vigorous activity per day was 3.9±4.4mins. There was no significant association between activity levels and age ($r = -0.643$, $p=0.085$) or body mass index ($r = -0.51$, $p = 0.197$).

Compliance with wearing the accelerometers was moderate. Our pilot data suggests some adults with Down syndrome may not engage in the recommended amount of MV physical activity, suggesting they are at high risk of diseases associated with a sedentary lifestyle. There is no association between activity level, age and BMI.

Talents and Achievements

The Congress includes a number of Poster presentations; DVDs and live performances by people with Down syndrome to showcase their many Talents and Achievements. A dedicated area in the Helix building houses poster presentations and DVDs, and there are also a number of presentations and live performances included throughout the Congress programme. Contributors to the Talents and Achievements section of the Congress include:

- **Tahnee Afuhaamango**, International Swimmer awarded Institute of Sport Scholarship, Australia
- ***Be My Brother***, award winning short film Tropfest Film Festival, Australia
- **Emmanuel Bishop**, *Emmanuel's Story* his achievements & violin performance
- **Stuart Campell & James Withers**, *'Celebrating Success, shaping tomorrow's future: Young people with Down's syndrome and Scottish Youth Parliament'*, Scotland
- **Lorainne Clarke**, *Independence is really about Self-Confidence* Video - NSW
- **Club Slick**, Rock and Roll Dance Group, Australia
- **Sujeet Desai**, International Pianist, USA
- **Community Through a Lens**, Photography Project, Limerick, Ireland
- **Karen Gaffney**, International swimmer & ambassador for Down syndrome USA
- **Rachel High**, Freelance Performing Artist *Stepping Stones to University* South Australia
- **Hot Fuzz Leadership Group**, Dublin, Ireland
- **Dylan Kuehl**, DK Arts, Washington, USA
- **Erin Lane**, Poet, Vancouver, Canada
- **Bryan Lambke**, Arizona, USA
- **Mayo Kayaking Club**, Mayo, Ireland
- **Meghan McLaughlin**, 'My Life Story', Donegal, Ireland
- **United by Music, Blues and Swing Band**, The Netherlands
- **Unlock Your Potential.ie**, Dublin, Ireland
- **Prabhakar Vishwanathan**, India
- **Judith Scott,** Artist

List of Presentations by Topic

Index

Index

Index

Rooms of presentation are coded:
MH (MAHONY HALL)
TH (THEATRE)
BS AND CODE (BUSINESS SCHOOL)
NS AND CODE (NURSING SCHOOL)

List of Presenters by Surname

SURNAME	FIRST INITIAL	IDNUM	Room allocation	Page
Adam	A	P34	Helix	76
Alawadi	S	P12	Helix	71
Amirimajd	M	O38	BS QG21	32
Attwell /Rickard	A & D	P65	Helix	84
Attwell / Rickard	A & D	O126	NS HG23	65
Baccichetti	C	P8	Helix	69
Bajraktar	D	O83	BS QG27	48
Baksi	L	O57	NS HG22	36
Baksi	L	O112	NS HG23	55
Baksi	L	P17	Helix	72
Baksi	L	P48	Helix	80
Bennett	S	P49	Helix	80
Bilboa	E	P80	Helix	89
Bird	G	ME16	BS Q121	61
Bird	G	PL19	MH	60
Bishop	E	O81	BS QG27	47
Bonertz	C	P55	Helix	82
Bourke	J	O49	NS HG20	34
Brierley	N	P6	Helix	69
Brown	V	O30	BS Q121	30
Brown	R	O99	BS Q122	52
Brown	R	PL23	MH	61
Brown	R	ME21	MH	62
Buckley	S	O98	BS Q122	52
Buckley	S	ME17	BS QG13	62
Buckley	S	O125	NS HG20	64
Burgoyne	K	O16	BS QG15	26
Cahalane	D	O116	NS HG22	56
Caulfield	M	O2	MH	22
Claes	P	O44	NS HG17	33
Clarke	G	O39	BS QG21	32
Clarke	G	O42	BS QG21	33
Condeço	T	O11	BS QG15	24
Condeço	T	O107	NS HG20	54
Condeço	T	P29	Helix	75
Contardi	A	O93	BS Q121	50
Contardi	A	O96	BS QG21	51
Cotrim	L	P45	Helix	79
Cotrim	L	P64	Helix	84
Cuffe	M	P25	Helix	74
Cuskelly	M	O22	BS QG27	28
Dalton	A	O86	BS Q121	49
Dawkins	T	P40	Helix	78
De Andrade	C	O66	MH	43
De Freminville	B	P22	Helix	73
de Graaf	G	O76	BS QG13	46
de Graaf	G	P30	Helix	75
de Graaf	G	P44	Helix	79
Desai	S	O18	BS QG13	27
Desai	S	O67	TH	44
Dickson	I	O9	TH	24
Doherty	U	PL18	MH	60
Doherty & Egan	U & M	ME15	NS HG20	61
Dolva	A	O128	NS HG23	66
Dupas + Group	C	O94	BS Q121	51
Dzurova	D	O73	BS QG15	45
Edwards	M F	O77	BS QG13	46
Edwards	K	O74	BS QG15	44
Edwards	MF	P67	Helix	85
Edwards	K	P73	Helix	87
Eidelman	S	PL24	MH	61
Eidelman	S	ME22	NS HG23	62
Enestram	P	P11	Helix	70
Engelbrecht	A	O78	BS QG13	47
Escamilla	S	O25	BS QG27	29
Escamilla	S	O26	BS QG27	29
Faragher	R	O104	NS HG20	53
Faramarzi	S	O3	MH	22
Farrell	M	O75	BS QG15	46
Feeley	K	ME18	BS Q27	62
Feeley	K	PL20	MH	60
Flanagan	G	O60	NS HG22	37
Flint	K	O32	BS Q120	30
Forti	S	P33	Helix	76
Foster-Cohen	S	P32	Helix	76
Gaffney	K	O6	TH	23
Gaidarji	E	P43	Helix	79
Gannon	M	ME4	BS QG15	21
Gannon	M	PL1	MH	20
Gannon	M	O43	BS QG22	33
Gavin	M	P19	Helix	72
Gavin	M	O20	BS QG13	27
Grant	R	O122	BS QG13	64
Guthrie Medlen	J	ME9	BS Q121	42
Guthrie Medlen	J	PL11	MH	40
Haelewyck /Champeaux	MC & JP	P38	Helix	77
Halder	C	PL7	MH	21
Hallner / Bostrom	M &R	P53	Helix	81
Harman	B	O79	BS QG13	47
Hasegawa	T	P70	Helix	86

List of Presenters by Surname

SURNAME	FIRST INITIAL	IDNUM	Room allocation	Page
Hazizul Hasan	M	P35	Helix	75
Heerensperger	D	P9	DSMIG O +Helix	70
Hennequin	M	O124	NS HG20	64
Hernández	P	O110	NS HG23	55
High	R	O109	NS HG23	54
Hingsburger	D	PL2	MH	20
Hingsburger	D	PL13	MH	40
Hingsburger	D	ME5	TH	21
Hingsburger	D	ME14	TH	42
Hoey	H	PL8	MH	40
Hughes	J	O58	NS HG22	37
Jackson	P	O33	BS Q120	31
Jeyes	G	P63	Helix	84
Jones	J	P3	Helix	68
Joosa	E	O84	BS QG27	48
Kelmendi	M	O64	MH	43
Keohane	S	O69	TH	44
Kirk	ML	P50	Helix	80
Kliewer	C	O15	BS QG15	26
Kuehl	D	O92	BS Q121	50
Kyrkou	M	O65	MH	43
Lambke	T	O100	BS QG22	52
Lane	E	P72	Helix	86
Lastella	A	P39	Helix	77
Layden	E	O114	NS HG22	56
Leach	M	O34	BS Q120	31
Lemons	C	O13	BS QG15	25
Lemons	C	P54	Helix	81
Leonori	C	O10	TH	24
Little	J	P24	Helix	74
Loebus	A	O119	BS QG15	63
Loebus	A	P47	Helix	80
Loebus	A	P60	Helix	83
London	J	O120	BS QG13	63
London	J	O117	NS HG22	56
Lopez-Morales	P	P16	Helix	72
Lopez-Oliver	X	O17	BS QG13	26
López-Pérez	R	P58	Helix	82
Lowry	D	P68	Helix	85
Lowry	D	P69	Helix	85
Mac Cobb	S	P51	Helix	81
Mac Donald	E	O40	BS QG21	33
MacDonald	D	O14	BS QG15	25
Macken	S	PL6	MH	21
Macken	S	ME2	NS HG20	21
Mahoney	G	O1	MH	22
Mahoney	G	O123	NS HG20	64
Marder	L	PL9	MH	40
Marder	L	ME6	MH	41
Marques	A	P57	Helix	82
Martin	K	P5	Helix	69
Martins	S	O5	MH	23
Matthews	L	P37	Helix	77
Mattheis	P	O55	NS HG23	36
Mayer	A	O35	BS Q120	31
Mayer	G	O102	BS QG22	53
Mayer	G	O103	BS QG22	53
Mayer	A	O51	NS HG23	35
McAlpine	C	O111	NS HG23	55
McAlpine	C	P71	Helix	86
McAlpine	C	P78	Helix	88
McCallion	P	O90	BS Q121	50
McCarron	M	O88	BS Q121	48
McCarron	M	O89	BS Q121	49
McConkey	R	ME20	BS QG15	60
McGowan	M	P77	Helix	88
McGuire	D	PL12	MH	40
McGuire	D	ME8	NS HG22	41
McConkey	R	PL22	MH	62
Mehta	P	O87	BS Q121	49
Molloy	A	O71	TH	45
Monari Martinez	E	O108	NS HG20	54
Monari Martinez	E	P41	Helix	78
Morales	G	P26	Helix	74
Morales	G	O68	TH	44
Mulryan	N	O113	NS HG22	55
Murphy	J	ME7	BS QG15	41
Murphy	J	PL10	MH	40
Ni Cholmain	C	PL15	MH	41
Ni Cholmain	C	ME11	NS HG22	42
Norouzi	G	P74	Helix	87
Norris	D	P31	Helix	75
Nunn	J	O62	MH	42
O'Brien	P	PL21	MH	60
O'Brien	P	ME19	TH	62
O'Bryan	A	PL25	MH	61
O'Bryan	A	ME23	NS HG22	63
O'Keeffe	M	O85	BS QG27	48
Opolski	J	O46	NS HG20	34

Index

Rooms of presentation are coded:
MH (MAHONY HALL)
TH (THEATRE)
BS AND CODE (BUSINESS SCHOOL)
NS AND CODE (NURSING SCHOOL)

World Down Syndrome Congress 2009

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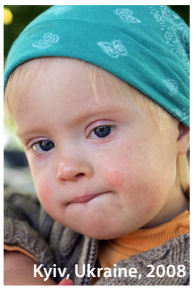
Kyiv, Ukraine, 2008


Misore, India, 2008

Down Syndrome Education International helps more than 80,000 people in over 180 countries every year.

Our pioneering scientific research, practical publications, training, consulting and outreach services deliver effective support to thousands of families, professionals and organisations every day.

Our work creates better learning opportunities, transforming the lives of many thousands of young people with Down syndrome.

Find out more about what we can do for you.

Visit our exhibition stand or www.downsed.org


Chennai, India, 2008


Sarajevo, Bosnia, 2009

Sacramento, USA, 2009


Manchester, UK, 2009

Down Syndrome Education International
www.downsed.org

The Sarah Duffen Centre
Belmont Street
Southsea PO5 1NA
UK

Email enquiries@downsed.org
Tel +44 23 9285 5330

UK registered charity no. 1062823

Down Syndrome Education USA
www.downsedusa.org

1451 Quail Street, Suite 104
Newport Beach
California 92660-2747
USA

Email info@downsedusa.org
Tel +1 949 757 1877

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