WORLD DOWN SYNDROME DAY
“My Friends, My Community” — The benefits of inclusive environments for today’s children and tomorrow’s adults

Conference Room 1
United Nations Headquarters
New York

21 March 2016

PROGRAMME
By adopting the ambitious and universal 2030 Agenda for Sustainable Development, the international community has promised to leave no one behind. This requires empowering children and adults with disabilities, including those with Down syndrome, to contribute to our common future.

Persons with disabilities, including those with Down syndrome, are more than persons in need of assistance; they are agents of change who can drive progress across society – and their voices must be heard as we strive to reach the Sustainable Development Goals.

Toward that end, I recall the words of Pablo Pineda, the actor and writer with Down syndrome. He has called on others with Down syndrome to perceive their own vast capabilities, saying, “They should see themselves as people who can achieve their goals.”

I would add that others in society should similarly appreciate the potential and power of the members of our human family with Down syndrome.

This affirmation should be backed by concrete steps to respect, protect and promote the rights of all persons with disabilities, including those with Down syndrome. I especially call for priority actions to improve opportunities for girls and women with disabilities who often face greater exclusion than boys and men.

On this World Down Syndrome Day, let us resolve to support the autonomy and independence of persons with Down syndrome, including their freedom to make choices, as part of our broader efforts to usher in a life of dignity for all.
MESSAGE FROM PRESIDENT OF DOWN SYNDROME INTERNATIONAL FOR WORLD DOWN SYNDROME DAY CONFERENCE

“MY FRIENDS, MY COMMUNITY – THE BENEFITS OF INCLUSIVE ENVIRONMENTS FOR TODAY’S CHILDREN AND TOMORROW’S ADULTS”

21 March 2016

Your Excellencies, distinguished guests and friends,

As President of Down Syndrome International (DSi), it gives me great pleasure to welcome you to the 5th World Down Syndrome Day (WDSD) Conference at United Nations (UN) Headquarters in New York. Happy World Down Syndrome Day 2016!

This Conference and DSi’s wider WDSD 2016 campaign owes a lot to the resolution of the UN General Assembly in December 2011 to recognize 21 March as World Down Syndrome Day.

For WDSD 2016, we are focusing on ““My Friends, My Community” - The benefits of inclusive environments for today's children and tomorrow's adults.” Our aim is to mobilise people with Down syndrome, their families, friends and advocates, to raise awareness both about the rights of people with Down syndrome to be fully included, on an equal basis with other people, in their communities, as well as promote the benefits of inclusive environments for everyone.

People with Down syndrome, on an equal basis with other people, must be able to enjoy their full and equal rights, both as children and adults. This includes the opportunity to participate fully in their communities.

The reality for many is that prevailing negative attitudes result in low expectations, discrimination and exclusion, creating communities where children and adults with Down syndrome cannot integrate successfully with others.

When children with Down syndrome and other disabilities are given opportunities to participate, all children benefit from this shared environment of friendship, acceptance and respect for everyone and high expectations are created.

In addition, these environments prepare all today’s children for life as tomorrow’s adults, enabling adults with Down syndrome to live, work and participate, with confidence and individual autonomy, fully included in society alongside their friends and peers.

This campaign draws from the UN Convention on the Rights of Persons with Disabilities (UN CRPD) Article 7, ensuring the full enjoyment by children with disabilities of all human rights and fundamental freedoms; Article 24, ensuring persons with disabilities are not excluded from the general education system on the basis of disability; Article 19, facilitating full inclusion and participation in the community of persons with disabilities and all CRPD Articles which ensure the opportunity of persons with Down syndrome to participate fully as children and adults.

The campaign also draws from the 2030 Agenda Sustainable Development Goals (SDG’s); Goal 4, ensuring inclusive and equitable quality education; Goal 8, promoting sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all; Goal 16, promoting peaceful and inclusive societies for sustainable development and all SDG’s which will ensure the opportunity of persons with Down syndrome to participate fully as children and adults by 2030.

At today’s conference, our excellent panellists will comprise a mix of persons with Down syndrome, family members and friends with personal insight of inclusion within their communities, Government and UN officials, NGO representatives with
professional experience and acknowledged experts in these fields. As always, we have made efforts to invite qualified 
speakers from a diverse range of countries and world regions.

This conference will work to realise the rights of persons with Down syndrome to be included, show how inclusion works in 
practice and the benefits to society of inclusive environments and will start a DSi-led effort to establish best practice 
guidance on inclusion.

Down Syndrome International is extremely grateful to our sponsors, The Permanent Missions of Australia, Brazil, India, Iran, 
Israel, Japan, Republic of Korea, Luxembourg, Mongolia, New Zealand, Poland, Qatar, Singapore and United Kingdom to 
the United Nations, UN Department of Economic and Social Affairs (DESA), UNICEF, International Disability Alliance and 
Inclusion International. We would also like to acknowledge and thank Senator Lindbergh from Brazil who is here with us 
today and who supported the original initiative which led to the recognition of WDSD by the UN.

Most importantly I would like to acknowledge today’s self-advocate speakers for their support and passion to contribute and 
express themselves and of course people with Down syndrome around the world.

I trust that you will enjoy the day with us and I thank you for your participation!

Yours sincerely,

SUREKHA RAMACHANDRAN
PRESIDENT
DOWN SYNDROME INTERNATIONAL
2016 WORLD DOWN SYNDROME DAY CONFERENCE PROGRAM
Conference Room 1, United Nations Headquarters
21 March 2016

10:00am - 10:45am
Official Opening and Launch of World Down Syndrome Day Conference “My Friends, My Community – The benefits of inclusive environments for today’s children and tomorrow’s adults”
With the adoption of United Nations General Assembly Resolution 66/149, the international community agreed to formally recognize World Down Syndrome Day every 21 March, to continue to raise public awareness of Down syndrome. The resolution also calls upon the international community to continue to advocate for the rights of those with Down syndrome. The speakers on this opening panel will touch on the multiple ways that United Nations Member States and agencies across the UN system are addressing this topic.

Welcome & Introductions – Message from Dr. Surekha Ramachandran, President, Down Syndrome International
H.E. Mr. Oh Joon – Ambassador and Permanent Representative of the Republic of Korea to the UN and President of the Conference of State Parties to the CRPD
H.E. Mr. Antonio de Aguiar Patriota – Ambassador and Permanent Representative of Brazil to the UN
H.E. Mr. Boguslaw Winid – Ambassador and Permanent Representative of the Republic of Poland to the UN
H.E. Mr. Motohide Yoshikawa – Ambassador and Permanent Representative of Japan to the UN
H.E. Mr. Sukhbold Sukhee – Ambassador and Permanent Representative of Mongolia to the UN
H.E. Mr. Martin Shearman – Ambassador for Development, Human Rights and Peacebuilding, United Kingdom Mission to the UN
Ms. Catalina Devandas Aguiar – UN Special Rapporteur on the Rights of Persons with Disabilities (video)

Moderator: Emoke Bebiak, UN Correspondents Association, German Press Agency (10am -1pm)

10:45am – 11:00am
Keynote Address
Dr. Surekha Ramachandran – President, Down Syndrome International, India, ““My Friends, My Community” - The benefits of inclusive environments for today's children and tomorrow's adults”
Includes WDSD 2016 Global Video Event #MyFriendsMyCommunity

11:00am – 12:00pm
The importance of including children and adults with Down syndrome. Their right to be included. How inclusion benefits those persons, their peers, their families, the local community and society.

Joanna Hajduk (self advocate) – Poland, “Being included/excluded from the society because of Down syndrome – personal experience”
Torrie Dunlap – CEO, Kids Included Together, USA, “An Inclusion Revolution that Started with One Boy”
Ana Lucia Villela and Dr. Todd Grindal – Founder and Chair, Alana Institute, Brazil and Senior Associate, Abt Associates, “Investing in Research to Accelerate Inclusion in School” and “Evidence from Research on the Effectiveness of Inclusive Education”

12:00pm – 1:00pm
How to ensure that children and adults experience inclusive settings and environments.
Examples, case studies, testimonials.

Aleksandar Matovski (self-advocate) – Macedonia, “Young People and Down Syndrome”
David Weingarten – Vice-Chair, Let All the Children Play Foundation, USA, “Inclusion for All – Yesterday, Today and Tomorrow”
Vanessa dos Santos – Vice President, Down Syndrome International, South Africa, “Creating Enabling Environments”
Benjamin Maor – Director, International Resource Development, Beit Issie Shapiro, Israel, “Changing Attitudes as Leverage for Social Inclusion”

1:15pm – 3:00pm
Side Event - High Level Panel to #Endviolence against Children and Adolescents with disabilities, includes Tathiana Piancastelli (self advocate); Sponsored by UNICEF; held at UNICEF House

1:15pm – 2:30pm
Side Event: - Changing Stereotypes against People with Down Syndrome: The Real Meaning of Mongolia; Permanent Mission of Mongolia to the United Nations; Conference Room 7
3:00pm – 4:15pm  Inclusion in early childhood as a pathway to inclusion in society as adults – living, working, and participating in community. Examples, case studies, testimonials.

Moderator: Maria Antonia Goulart, National Work Group of Creativity and Innovation, Brazil
Antoine Fontenit (self advocate) – France, “We are All Citizens”
Bridget Snedden – Trustee, Down Syndrome International, Deputy Chair, Spectrum Care Trust Board and Member, New Zealand Down Syndrome Association, New Zealand, “Getting on with Life – playing, learning, and living in community alongside neighbors and friends”
Amarild Leka – Albania, “The Albanian Challenge”
Fernando Heiderich – Senior Director, MetaSocial Institute and CEO, Piancastelli & Heiderich Consulting, Brazil, “Paving the way for a win-win future for all”
Dr. Jun Ishikawa – Chair, Commission on Policy for Persons with Disabilities, Cabinet Office, Government of Japan and Professor, Department of International Relations, University of Shizuoka, and Project Professor, Research Center for Advanced Science and Technology, University of Tokyo, Japan, “Social and Political Participation of Persons with Intellectual Disabilities”

4:15pm – 4:30pm  Break

4:30pm – 5:45pm  The role of inclusion in creating attitudinal change in society as a whole. The emergence of people with Down syndrome in public life, in the media, etc.

Moderator: John Blascovich, President, The Matthew Foundation, USA
Anna Rose Rubright (self advocate) – United States, “How I See Myself... A Happy and Productive Life”
Catia Malaquias – Director, Down Syndrome Australia, “Powering inclusion: Changing cultural perspectives of Down syndrome and disability through inclusive imagery and messages”
Martina Fuga – Board Member, CoorDown ONLUS, Italy, “How to build an inclusive culture: Understanding Down syndrome through the lens of diversity”
Uuganaa Ramsay and Enkhtsetseg Tserendash – Author and Executive Director, Down Syndrome Association Mongolia (respectively), “Language Matters – The Meaning of Mongol” and “Attitude and Social Inclusion – Current Situation in Mongolia”

5:45pm – 6:00pm  Closing Session

Andrew Boys, Director, Down Syndrome International

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Organized by Down Syndrome International

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CATALINA DEVANDAS AGUIAR
Special Rapporteur on the Rights of Persons with Disabilities, Costa Rica
Ms. Catalina Devandas Aguilar (Costa Rica) is a lawyer by training and human rights advocate, who has worked extensively on disability issues at the national, regional and international level. Before taking up her duties as first Special Rapporteur on the rights of persons with disabilities on 1 December 2014, she was working as a Program Officer for Strategic Partnerships with the Disability Rights Advocacy Fund, and was formerly with the United Nations Secretariat unit responsible for the Convention on the Rights of Persons with Disabilities (CRPD) and the World Bank as a consultant for the Disability and Inclusive Development team for Latin America and the Caribbean region. Ms. Devandas Aguilar has previously served as a Board Member of the Latin American Network of Persons with Disabilities representing the region in the International Disability Alliance.

Her works has focused on the rights of women with disabilities and the rights of indigenous peoples with disabilities, and she has experience supporting capacity building and technical assistance projects with Governments, United Nations system actors, national human rights institutions, and organizations of persons with disabilities.

EMOKE BEBIAK
Journalist, German Press Agency and United Nations Correspondents Association
Emoke Bebiak has worked as a United Nations correspondent for the German Press Agency (dpa) since 2013. Previously, she reported from Washington, DC and South Africa. She holds a Master’s degree from the Missouri School of Journalism.

JOHN BLASCOVICH
President, The Matthew Foundation, USA
John Blascovich is President and Chairperson of The Matthew Foundation Inc. He is a Partner with A.T. Kearney, a global management consulting firm, and leads AT Kearney’s Operations and Performance Transformation and Procurement and Analytics Solutions (PAS) practices. John has also served a four year term on the Board of Directors of the Institute for Supply Management (ISM).

The Matthew Foundation’s mission is to improve the quality of life for all people with Down syndrome over their entire lifespan and focuses on research and care, inclusive practices, and employment initiatives. The Matthew Foundation established the first and currently only endowed fund at Stanford University dedicated to Down syndrome research. In February 2016, The Matthew Foundation organized Super Fest, an inclusive football and cheerleading clinic with NFL alumni the day before Super Bowl 50 in San Francisco. Super Fest was applauded by participants and the broader community and received coverage by ESPN.

John earned a bachelor’s and master’s degree in Aeronautics and Astronautics from the Massachusetts Institute of Technology (MIT) and an MBA from New York University.
ANDREW BOYS
Director, Down Syndrome International, United Kingdom

Andrew Boys has been the Director of Down Syndrome International since the launch of the DSi secretariat in 2009 in the UK, working with DSi’s Board of Trustees to establish a global membership network in 140 countries, promoting the inherent right of people with Down syndrome to be accepted and included as valued and equal members of their communities.

For the last 7 years, Andrew has led DSi’s World Down Syndrome Day campaign, including the global sharing website www.worlddownsyndromeday.org, WDSD global video event and the successful WDSD Conferences following the UN General Assembly resolution (passed in December 2011) officially recognising WDSD on 21 March each year.

Andrew established DSi’s “Reach Out” outreach training programmes to enable people with Down syndrome facing limited life opportunities, their families and those who live and work with them, to access expert advice, information, support and resources, with successful projects taking place in Tajikistan, Oman and India in 2013, 2014 and 2015 respectively.

In a former life Andrew was a chartered surveyor in London. Andrew’s younger brother Alex is a motivated, independent young man …he also has Down syndrome.

VANESSA DOS SANTOS
Vice President, Down Syndrome International, South Africa

Vanessa has a son with both Down syndrome and Cerebral Palsy and has been involved in the disability sector since 1995, striving for the rights of people with disabilities and in particular intellectual disabilities, both nationally and internationally.

She is the past Chairperson and Director of Down Syndrome South Africa. During this time she was instrumental in setting up outreach groups in the poverty stricken areas in South Africa and founder of the Self Advocacy Movement of South Africa and the African Down Syndrome Network.

Vanessa completed her Masters in Philosophy (MPhil) in Disability Studies in 2011 from the University of Cape Town. In 2012 she was elected as the President of Down Syndrome International until 2015 and is now the Vice President of the organisation. She was recently elected as the incoming co-vice chair of the International Disability Alliance. She has given many presentations nationally and internationally and has written many training manuals and modules to improve the lives of people with intellectual disabilities and their families.

She has received numerous awards for her achievements for the work that she has done in the past.

TORRIE DUNLAP
Chief Executive Office, Kids Included Together, USA

In 1998, Torrie Dunlap found her life’s purpose when she taught a theater class for children that included a boy with Down syndrome. This is also how she came to know the work of Kids Included Together (KIT), a nonprofit where she started as a volunteer and today is the Chief Executive Officer. KIT teaches inclusive practices to people and organizations that serve children. Torrie has delivered keynotes and trainings on inclusion around the United States and in Canada and Europe, and has been published in textbooks, professional journals, trade magazine and on several popular blogs, including Disability.Gov. Torrie is a Certified Professional in Learning and Performance and has been selected for social innovation fellowships at both Stanford University Graduate School of Business and Harvard Business
ANTOINE FONTENIT  
Self-advocate, Trisomie 21, France

Antoine Fontenit is 28 years old and lives independently. He works in a sheltered workshop. As any French citizen, Antoine has the right to vote and he is proud of exercising it. He is the vice-president of the local organization Trisomie 21 Vendée. As such, he pushed ahead with a project called ‘Mes Amours’, about affective and sexual relationships for people with DS. In this project Antoine will become a coach for other people with DS. Antoine is also a self-advocate for Trisomie 21 France. Antoine considers it his duty as a citizen to support people with DS in the exercise of their own citizenship. With a group of self-advocates he took part in the selection of various projects to be funded by the ‘Fondation de France’.

As a citizen, Antoine knows that he has a role to play in fostering the emergence of an inclusive society where everyone can have the opportunity to make their own choices. He knows he can make a difference.

MARTINA FUGA  
Board Member, CoorDown ONLUS, Italy

Martina Fuga was born in Venice and lives in Milan. She is the mother of 3 children and her daughter Emma (11 years) has Down syndrome. She has been involved with the Down syndrome community since the birth of Emma in 2005, serving associations and collaborating to different fundraising program. She is a Coordown ONLUS board member and their delegate for communication and fundraising. She is also a member of the board of AGPD Onlus (Milan Down Syndrome Association) and president of Pianetadown Onlus (Italian association and online forum for parents, relatives, teacher of person with Down syndrome.)

Martina graduated from Ca’ Foscari University of Venice in Oriental Languages and Literatures, specializing in Art History. She is a Contract Professor about Managment of Art and Cultural Heritage, Catholic University of Milan (Masters degree program) and an art consultant for Ballandi Arts for art documentaries broadcasted on SkyArte. She has also served as Director for an art exhibition company. Martina founded Artkids, a company that introduces children to the world or art. She is currently working on a project to integrate people with Down syndrome in museums. Martina published the book Emma’s Backpack (Lo zaino di Emma) by Mondadori on her experience as mother of Emma. Emma is one of the 13 protagonist of the film “Dear Future Mom” produced last year for World Down Syndrome Day by Coordown and Saatchi and Saatchi.

MARIA ANTONIA GOULAR  
National Work Group of Creativity and Innovation, Brazil

Maria is a member of the National Work Group of Creativity and Innovation, created by the Ministry of Education (MEC). She graduated in Law at the University of Brasília and has experience in the public sector as municipal secretary of Nova Iguaçu/RJ, being responsible for the conception and implementation of "Neighborhood-School", an Integral Education Program, from 2005 to 2010. Coauthor of the book “Caminhos da Educação Integral no Brasil” (Paths of Integral Education in Brazil), Maria is general coordinator of MAIS – Movimento de Ação e Inovação Social (Organization of Action and Social Innovation) and of Movimento Down (Down Organization). She is also Brazil’s coordinator of the UNICEF initiative for the accessible digital book and a member of the Steering Committee of the Reference Center for Integral Education.
TODD GRINDAL
Senior Associate, Abt Associates, Julius B. Richmond Fellowship, Harvard University Center on the Developing Child, and Emerging Education Policy Scholar, Fordham Foundation and American Enterprise Institute, USA

Todd Grindal Ed.D is a senior associate with Abt Associates where he studies the impact of public policies on young children and children with disabilities. Dr. Grindal studied at the Harvard University Graduate School of Education where he was awarded a Julius B. Richmond Fellowship by the Harvard Center on the Developing Child in support of his dissertation research on the unionization of home childcare providers. He is also a recipient of the 2009 Meade Fellowship from the Institute for Educational Leadership and has been recognized as an Emerging Education Policy Scholar by the Fordham Foundation and American Enterprise Institute. Prior to beginning his doctoral studies, Dr. Grindal worked for six years as a teacher and school administrator at the high school level in Florida, and at the elementary school and preschool levels in the Washington, D.C. metropolitan area. He earned a B.A. in History from The New College of Florida and an Ed.M. and Ed.D from the Harvard Graduate School of Education. Dr. Grindal also writes an occasional blog on education policy and practice for the Huffington Post.

JOANNA HAJDUK
Self Advocate, Poland

Joanna Hajduk was born on 11 August, 1983. She lives in Warsaw, Poland. Since she was eight years old she participates in the Occupational Therapy Workshop organized by the Board of the Polish Association for Persons with Intellectual Disabilities in Warsaw (PSOUU). Joanna actively participates in the projects of the Multimedia Laboratory, like:

- co-creating radio shows, which were then broadcasted on the Internet Radio SoVo-Sounds and Voices (http://www.psoou.org.pl/archiwalne-audycje-radia-sovo), operating since 2013 as part of the Lifelong Learning project,
- using and testing of educational games, posted on educational portals,
- checking for easy to read and understand texts, published by PSOUU and others.

She is the leader of the Warsaw Group of Self-Advocates. In 2010 she was a member of the Polish delegation participating in the annual conference "Europe in Action", organized by Inclusion Europe which was held in Tampere, Finland. She participated in foreign trips to Romania (2013) and Italy (2014), organized within the European projects Leonardo da Vinci and Erasmus+. In 2013, she participated in a panel discussion "Civil rights", organized as part of the debate "The place and role of people with intellectual disabilities in a modern democratic society", held in the Polish Parliament, to celebrate the Day of Dignity of Persons with Intellectual Disabilities. Participants of the debate were the Ombudsman, a judge of the Constitutional Court, Members of Parliament and people with disabilities).

She likes kayaking, jigsaw puzzles (the more pieces and complicated picture the cooler), travels and social contacts. He has a great sense of humor.

FERNANDO HEIDERICH
Senior Director, MetaSocial Institute, Brazil

Fernando Heiderich has worked over 30 years on the animal health industry and resigned from his last position as Global Marketing VP at Merck AH at the end of 2014 to dedicate a greater part of his life to help disable people to be included. He has been an active member of MetaSocial Institute, Brazil, since its founding in 1993.

Before moving to Miami in 2015, Fernando lived in New Jersey for 2 years after spending 3 years in The Netherlands. Previous to his international career, he was general manager in Brazil for 9 years.

He has practiced as a field veterinarian (1981-1983) and subsequently has held several positions of increasing responsibility in the animal health industry at Merck, Sharp & Dome AGVET (1983-1989), Fort Dodge (1990-1996) and Schering-Plough (1997-2010).

Fernando was nominated Ambassador by the Brazilian Veterinary Medicine society (2004), holds a Veterinary Doctor degree from UEL, the University of Parana State in Londrina (1981, Brazil), an MBA from Penn State University (1994, USA) and a Developing Leadership - Center for Creative Leadership, USA - 1995.
JUN ISHIKAWA  
Chair, Commission on Policy for Persons with Disabilities, Cabinet Office, Government of Japan, Professor, Department of International Relations, University of Shizuoka, Japan, and Project Professor, Research Center for Advanced Science and Technology, University of Tokyo, Japan  

Dr. Jun Ishikawa, who is blind, is one of the most highly qualified scholars and professionals in Japan in the field of Disability Studies and Assistive Technology. He is the current Chair of the Commission on Policy for Persons with Disabilities in the Cabinet Office of the Government of Japan, a national framework to promote, protect and monitor the implementation of the Convention on the Rights of Persons with Disabilities. Throughout his long career, Dr. Ishikawa has contributed greatly to academic development in the sociological and technological fields of disability studies, including as a Professor at the Department of International Relations at the University of Shizuoka and as a Project Professor at the Research Center for Advanced Science and Technology at the University of Tokyo.

AMARILD LEKA  
Brother of Andi Leka, who has Down syndrome, Albania  

Amarild is Andi Leka’s older brother and best friend. Andi is 14 years old with Down Syndrome. Amarild is 26 years old. They are from Pogradec, Albania.

For the past four years, Amarild brings Andi to his therapies and never misses an event.

Amarild runs his family’s Agricultural Pharmacy. He holds an Environment and Agriculture Engineering degree. In addition to his native language, he speaks English and Italian.

CATIA MALAQUIAS  
Deputy Chair, Down Syndrome Western Australia, Director, Attitude Foundation, Founder, Starting with Julius, Australia  

Cátia is a lawyer and mother of three children. Her son, Julius (6 years), has Down syndrome. She is a Director of Down Syndrome Australia, the Deputy Chair of Down Syndrome Western Australia, a Director of the Attitude Foundation and the founder of Starting With Julius, a project to promote the inclusion of people with disability in mainstream advertising and media.

Cátia is passionate about human rights, inclusive education and inclusion for people with Down syndrome and other disability in every area of life. She is committed to these matters through her participation in various organisations as well as through the media and social media.

BENJAMIN MAOR  
Director, International Resource Development, Beit Issie Shapiro, Israel  

Benjy Maor has over 30 years of experience in the non-for-profit sector and began work as the Director of the International Resource Development Department at Beit Issie Shapiro in 2010.

Benjy works with partners around the world to enlist support in realizing Beit Issie Shapiro’s mission to ensure that every person with a disability should be a citizen with full equal rights, integrated and active in community life.
ALEKSANDAR MATOVSKI  
Self Advocate, Macedonia

Aleksandar Matovski was born on 03.02.1991 in Skopje, Macedonia. Despite being diagnosed with Down syndrome, he has been included in the mainstream educational system. He is currently finishing his studies at the Pedagogical Faculty in Skopje. Aleksandar is a member of the Executive Board of the Center for Youth Activism “KRIK”, which works with people with disability and is also an active member of Trisomija 21-Skopje and Down Syndrome Center- Macedonia. Aleksandar was an intern at the NGO “My career”, where he worked on mapping of all individuals with disability in Macedonia. He has participated in many projects about people with disabilities on the local level: “Activated talks”, “Inclusive dance Festival”, “Ball of diversity” and many others. Internationally, he had his European Volunteering Service (EVS) project for people with disabilities; he was UNICEF’s representative on the working meeting for development of post-2015 agenda for people with disability. Aleksandar has also presented his work in Banja Luka in Bosnia and Herzegovina and was a part of the Erasmus+ youth exchange dedicated to the inclusion of people with disability called “You will never walk alone”. At the moment, one of the most important individual projects of Aleksandar - Cako is “I am Cako”, his own radio show, on the internet radio “Radio MOF”. In his free time he writes poetry, dances, practices karate and photography.

MELANIE PERKINS MCLAUGHLIN  
Filmmaker, USA

Melanie Perkins McLaughlin is a documentary filmmaker, a disability rights advocate, public speaker and the mother of three children, the youngest of whom has Down syndrome.

In 2007 she independently produced film, “Have You Seen Andy?”, the personal story of the search for answers to the disappearance of her childhood friend, broadcast on HBO winning a National Emmy Award for Best Investigative Journalism. That same year Perkins McLaughlin received a prenatal diagnosis: her third child had Trisomy 21 and a congenital heart defect.

Since her daughter’s birth Perkins-McLaughlin has become a public spokesperson on disability and civil rights issues. She has been interviewed nationally by TIME magazine, CBS News, USA Today, HBO, ABC, Japanese Public Broadcasting (NHK), National Public Radio, Fox News and the BBC. She has presented on prenatal ethics and disability awareness issues with Harvard University Medical School, Tufts Medical School, Boston University School of Medicine and Brandeis University.

She is currently a First Call parent volunteer with the Mass Down Syndrome Congress where she offers a unique and non-judgmental perspective on prenatal diagnosis. She was the inaugural Allen C. Crocker Family Fellow with the Institute for Community Inclusion and the Massachusetts Developmental Disabilities Council. And she recently produced a series of short films for the National Down Syndrome Society’s “My Great Story” public awareness campaign. She is the co-chair of the Department of Elementary and Secondary Education Special Advisory Committee, a family faculty member of Boston Children’s Hospital Institute for Professional Ethics and a family faculty member for The Arc of MA Operation House Call. In the Spring of 2016 McLaughlin will begin a graduate program in Human Development and Psychology (Child Advocacy) at Harvard University.

H.E. MR. OH JOON  
Ambassador and Permanent Resident of the Republic of Korea to the United Nations

Ambassador Oh Joon is a career diplomat who has served the Republic of Korea in various posts. He was appointed as Ambassador and Permanent Representative of the Republic of Korea to the United Nations in New York on 20 September 2013. Prior to this position, he was Ambassador of the Republic of Korea in Singapore from 2010-13 and Deputy Minister for Multilateral and Global Affairs in the Ministry of Foreign Affairs and Trade in Seoul from 2008-10.

From 2005-2007, he was Ambassador and Deputy Permanent Representative at the Permanent Mission of the Republic of Korea to the UN. He served as Chairman of the United Nations Disarmament Commission for the 2006 session and represented the Republic of Korea in many meetings of the UN bodies. During the Korean presidency of the 56th session of the UN General Assembly from 2001-2002, he worked in the President’s office as Deputy Chef de Cabinet.
From 2003-2005, he was Director-General for International Organizations at the Korean Foreign Ministry. During this time, he also chaired the Missile Technology Control Regime.

He joined the Korean Ministry of Foreign Affairs in 1978 and has served as Special Adviser to the Foreign Minister; Minister, ROK Embassy in Brazil; Deputy Director-General for Policy Planning; Counselor, ROK Embassy in Malaysia; and Director United Nations Division. The ROK Government awarded him an Order of Service Merit twice, first the Order of Green Strips in 1996 and Order of Yellow Stripes in 2006.

He received a Master’s degree in International Policy Studies from Stanford University; a diploma in International and Comparative Politics from the London School of Economics and Political Science; and a Bachelor’s in French literature from Seoul National University. He was also a visiting scholar at Hoover Institution, Stanford University.

H.E. MR. ANTONIO DE AGUIAR PATRIOTA  
Ambassador and Permanent Resident of Brazil to the United Nations  

UUGANAA RAMSAY  
Author, Mongolia  
Uuganaa Ramsay is an award-winning author, campaigner and advocate. She was born in Mongolia and now lives in Britain. Uuganaa started writing and campaigning in 2010 after the death of her son Billy who had Down's syndrome. She has been campaigning against hate speech towards people with learning difficulties and disabilities and raising awareness of Down syndrome and of the origin of the word 'Mongol'. Uuganaa won the Scottish Asian Women’s Award For Achievement Against All Odds in 2014, recognizing her “achievements in the face of adversity and challenging circumstances – a true modern day heroine”. Her memoir "Mongol" won the Janetta Bowie Chalice Non-Fiction Book Award from the Scottish Association of Writers. BBC Radio 4 and BBC World Service produced a documentary "The Meaning of Mongol."

Uugana is an active member of online Down’s syndrome community and is actively involved with Down’s Syndrome Scotland and Mongolian Down Syndrome Association. She is a Careers Adviser and a member of Equalities Group at Skills Development Scotland. Her role involves working with young people with learning difficulties and disabilities and supporting them to achieve employment, training and independent living.

SUREKHA RAMACHANDRAN  
President, Down Syndrome International, India  
When Babli, her daughter, was diagnosed with Down syndrome, Dr Ramachandran refused to accept that there was no future for her child. She was determined to fight the system and create a better life for her and others. Battling a severe lack of information and discouragement from doctors, she took it on herself to help more parents like her and children like Babli. At the time there were no specialized centers for persons with Down syndrome, experts were limited, guidance and counselling was sparingly available and parents did not share their experiences. Dr Ramachandran founded the Down Syndrome Federation of India, a place where all necessary resources, guidance of specialists, allied health professionals and therapists were brought under one single roof.

Dr Ramachandran is passionate about the importance of early intervention for people with Down syndrome. She is currently President of Down Syndrome International (DSI) and has been contributing to the awareness of Down syndrome in India and worldwide through various lectures and books. She holds a PhD in Cognitive Deficits and Depression in Down Syndrome from University of Madras. Through her extensive and continued travel and research, Dr Ramachandran has kept herself abreast of developments in the dynamically changing scene of Down syndrome.
With love and care, Dr Ramachandran has inspired many families to cope and thrive with Down syndrome, with love and care. She has always emphasized the need for inclusive living for individuals with Down syndrome. She has written two books, both of which are a simple insight into ways of making people with Down syndrome feel as much a part of society as anybody else.

As President of DSi, her main objective is to spread awareness about Down syndrome and the rights of people with Down syndrome to live a full and ordinary life in society in developing countries, especially India, other SAARC countries and the Middle East.

In 1998, Dr Ramachandran was awarded the "Woman of the Year" Award for outstanding work in the area of creating awareness for Down syndrome, special training and therapy. In 2008, she was awarded the “For the Sake of Honour” Award from the Rotary Club for selfless devotion to the rehabilitation of persons with Down syndrome in India. In 2009, she received an IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities) Award in Singapore for her contribution to the world of Down syndrome.

Dr Ramachandran has personally cared for and counseled around 4,200 people with Down syndrome in India.

ANNAROSE RUBRIGHT
Self Advocate, National Down Syndrome Society, USA

AnnaRose attends Rowan College at Burlington County full-time as a Liberal Arts major, is a part-time employee at Breakthru Physical Therapy and Fitness, and is a self-advocate. Just ask her and she will tell you she is an excellent role model for her five younger sisters, as well as others with DS and young people in general. In 2014, at age 18, she earned her high school diploma, graduating as a member of the National Honor Society. AnnaRose is also active in her church and frequently volunteers to serve the altar at mass. AnnaRose’s greatest love is sports. AnnaRose swims and plays basketball for teams with the Special Olympics NJ and also participates in SONJ Unified teams for soccer and basketball. AnnaRose was a guest of the NY Red Bulls in the ticker tape parade after the USA Women’s National Soccer Team won the Women’s FIFA World Cup 2015.

An avid self-advocate, AnnaRose enjoys making her own life decisions, which has included dating, post-secondary education, and spending her money as she pleases. She is well known in her community for working with AMC Theaters in 2013 to develop to a better understanding of how the theater could serve patrons with intellectual disabilities. AnnaRose’s goals for the future include finishing her education, finding a full time job with benefits, dating someone smart and funny, and spending lots of time traveling. After working on the CoorDown video “How Do You See Me” with Reed Morano and Olivia Wilde, she has also decided that she should try acting.

CHRISTINE SARGEANT
Representative and Independent Researcher, Jasmine Society for Children, Jordan

Christine Sargent conducted 20 months of fieldwork in Amman, Jordan, where the Jasmine Society for Children with Down Syndrome, a member of Down Syndrome International, served as her host institution and local affiliation during her Fulbright Institute for International Education research grant. Christine is a doctoral candidate in Anthropology at the University of Michigan. Her dissertation looks at cross-cultural constructions of Down Syndrome, and asks how human rights discourses and instruments such as the UNCRPD interact with local understandings of difference, impairment, and disability. This project is connected to broader anthropological themes of care, kinship, and vulnerability in the contemporary Middle East. She holds a Masters in Anthropology from the University of Michigan and a B.A. in Middle East Studies from Pomona College.
H.E. MR. MARTIN SHEARMAN  
Ambassador of Development, Human Rights and Peacekeeping, United Kingdom Mission to the United Nations

Martin Shearmen is the Ambassador for Development, Human Rights and Peacebuilding at the UK Mission responsible for development and human rights issues since 2013. He is a career diplomat who has served in various postings in Africa, Japan and Europe during his career. Before coming to New York Martin was British High Commissioner to Uganda, where in addition to his official duties he was honoured to support the Katalemwa Cheshire Home for Rehabilitation Services for children with disabilities near Kampala.

BRIDGET SNEDDEN  
Trustee, Down Syndrome International, Deputy Chair, Spectrum Care Trust Board, and member, New Zealand Down Syndrome Association, New Zealand

Bridget Snedden is a first generation New Zealander and is of Tongan and Irish heritage. She has three adult children, her oldest son Alex (28yrs) has Down syndrome.

Bridget is a Trustee of Down Syndrome International and Deputy Chair of Spectrum Care Trust Board. She has been actively involved in the disability sector for over 20 years in a variety of roles; primarily working for NGOs where she acquired a good understanding of the roles that Government, community agencies and family have in the attainment of a ‘good and ordinary life for people with Down syndrome. Bridget is deeply committed to the inclusion of people with a disability and their inherent right to live in community with their neighbors and friends.

H.E. MR. SUKHEE SUKHBOLD  
Ambassador and Permanent Representative of Mongolia to the United Nations

Ambassador Sukhbold Sukhee presented his credentials to the Secretary-General of the United Nations on July 31, 2015.

From 1999-2015, he worked in the Ministry of Foreign Affairs of Mongolia as attaché, third secretary, second secretary, deputy director, acting director and director in the Departments of International Organizations, Legal and Consular Affairs, Law and Treaty and Public Administration and Management of MFA. From 2007-2010, he was posted as second secretary to the Permanent Mission of Mongolia to the United Nations.

He graduated from Moscow’s University of International Relations majoring in public international law in 1999 and completed his Master of Business Administration degree in Victoria University, Melbourne, Australia in 2006. Ambassador Sukhbold Sukhee is a Member, Executive Board of the Mongolian Cricket Association and Executive Director of MGIMO-Mongol NGO.
ENKHTSETSEG TSERENDASH  
Executive Director, Down Syndrome Association Mongolia  
Enkhtsetseg Tserendash has had an extensive business career that has included several Chief Financial Officer positions such as Banking, Financial and Auditing companies, Government and NGOs. During her 15-year employment in several sectors she obtained her Bachelor of Arts in Business Management at the National University of Mongolia and a Master of Business Administration degree in the United States. Enkhtsetseg’s experience of leading projects, and the budgets, timelines, and people that go along with them, has provided her with a well-rounded view of what businesses—and nonprofits—need to thrive. Enkhtsetseg brings to Down Syndrome Association Mongolia not only her educational and background experience but her love and compassion for people, desire to break down barriers, and commitment to serving the community.

Enkhtsetseg has been in her current position as Executive Director, Down Syndrome Association Mongolia since November 2015. Down Syndrome Association Mongolia (DSAM) was set up in 2008 by a group of parents of children with Down syndrome. DSAM is a non-profit organization which aims to work closely and regularly with healthcare and educational professionals, and voluntary charity organizations for the benefit of Mongolian children with Down syndrome.

ANA LUCIA VILLELA  
Founder & Chair, Alana Institute, Brazil  
Ana Lucia Villela founded and chairs Alana Institute, a non-profit organization whose mission is to honor the child. She graduated in Pedagogy and holds a master’s degree in Psychology of Education from PUC/SP. She is a member of the board of third sector institutions, such as Conectas Human Rights, Itaú Cultural, Akatu and Brincante Institute. Ana Lucia is also a member of the network of social entrepreneurs, Ashoka Fellow.

DAVID WEINGARTEN  
Vice Chair, Let All the Children Play Foundation, United States  
David Weingarten brings years of expertise to grassroots initiatives on Long Island for individuals with disabilities, most recently establishing the 2-acre playground project in Nassau County’s Eisenhower Park. David strives to stamp out inequities faced by families with children with disabilities. He was introduced to the funders and organization that spent years researching, developing and designing Israel’s first accessible playground, which opened in Ra’anana, Israel in 2005. Inspired, David established LATCP as a 501(c)(3) in 2006, collaborating with government officials, organizations, civic groups and parents in establishing a mission to create a similar playground in Nassau County.

Prior to the creation of LATCP, David provided the much needed service for families daunted by the enormous task of Special Needs Planning. David spent 9 years representing and advocating for individuals with disabilities as the Co-Chair of the Long Island Family Support Consumer Council, in conjunction with the LIDDSO (OPWDD). He serves as parent advocate for the Nassau County DOH Developmental Disabilities Committee. He is past president of the Association for Children with Down Syndrome, a former chair for the LI Multiple Sclerosis Golf Classic, and a certified Special Olympics coach. David holds a B.S.B.A from Denver University, and enjoyed a 20-plus year career in New York’s garment center. David currently works for the JCC of the Greater Five Towns (Marion & Aaron Gural JCC) as the Director of Special Needs/Projects and provides leadership with employment initiative for those with disabilities and runs much needed socialization programs for adults with disabilities.

David resides in Atlantic Beach with his wife Renee and two dogs. His son Adam lives in a group residence and attends a daily day program and his daughter Leah graduated Indiana University and works and lives in NYC. His leisure time recreation activities include golf, beach volleyball and basketball.
H.E. MR. BOGUSLAW WINID  
Ambassador and Permanent Representative of the Republic of Poland to the United Nations  

Boguslaw Winid is Ambassador Extraordinary and Plenipotentiary – Permanent Representative of the Republic of Poland to the United Nations in New York. He began his professional career in the Ministry of Foreign Affairs in 1991 in the Department of North and South America. 

Between 1992 and 1997, he served as First Secretary and later as Counsellor at the Polish Embassy in Washington, DC. In 1997, he returned to Warsaw and was promoted to Deputy Director and later Director of the Department of North and South America. In 2001, he was appointed Deputy Chief of Mission at the Embassy of Poland in Washington, DC. After returning from Washington in 2006, he became Undersecretary of State for Defence Policy at the Ministry of National Defence of Poland. From 2007 to 2011, he served as the Permanent Representative of Poland to NATO in Brussels. Boguslaw has been undersecretary of state of foreign affairs for consular matters, security, and North American and Middle East policies since 2011. 

Boguslaw Winid graduated from the Institute of History at Warsaw University. From 1988-1989, he studied at Indiana University, Bloomington, and at the Hoover Institution at Stanford University in 1991. In 1991, he also got his Ph.D. from Warsaw University. His doctoral thesis analyzed Polish-American relations between 1919 and 1939. It was published and awarded by the Institute of Political Studies of the Polish Academy of Sciences. Boguslaw Winid has written three books and several articles published in Poland, the United States and Great Britain. He speaks English and Russian. 

Boguslaw Winid was born in Warsaw on November 3 1960. He is married and has two sons.

H.E. MR. MOTOHIDE YOSHIKAWA  
Ambassador and Permanent Representative of Japan to the United Nations  

Ambassador Motohide Yoshikawa, Permanent Representative of Japan to the United Nations, was appointed to his current position in September 2013. 

Before his current appointment, Ambassador Yoshikawa served as Ambassador and Permanent Representative to the OECD in Paris from 2010. Prior to that, he served as Japan’s first Special Representative for Afghanistan and Pakistan from 2009-2010, and from 2006-2009 he served as Ambassador to Spain. Ambassador Yoshikawa also served as Director-General of the Middle Eastern and African Affairs Bureau of the Ministry from 2004-2006. His previous work with the United Nations includes serving as Director of the United Nations Policy Division of the Japanese Foreign Policy Bureau. He was also Visiting Professor at Ryukoku University in Kyoto. 

Ambassador Yoshikawa graduated with a degree in Social Sciences from the International Christian University (Tokyo) in 1974, and in the same year joined the Ministry of Foreign Affairs. He speaks Japanese, English, Spanish and French.
BACKGROUND INFORMATION

Resolution to recognize World Down Syndrome Day
World Down Syndrome Day was proclaimed in 2011 by the United Nations General Assembly resolution 66/149, to be observed annually. The resolution was proposed and promoted by Brazil, and co-sponsored by 78 UN Member States. From 2012 onward, the Day will be celebrated by all 193 UN Member States. The resolution is available at: http://www.un.org/disabilities/documents/resolutions/a_res_66_149.pdf.

World Down Syndrome Day
World Down Syndrome Day (WDSD) was first established by Down Syndrome International and has been celebrated since 2006, being observed in over 60 countries around the world. The aim of the Day is to raise awareness and increase the understanding about Down syndrome, to promote the inherent rights and dignity of persons with Down syndrome to enjoy full and dignified lives and to recognize the worth and valuable contributions of people with Down syndrome. The Day also works to ensure the inclusion of people with Down syndrome in every aspect of their community and society, in general. For more information about WDSD, visit www.worlddownsyndromeday.org.

Down Syndrome International
Down Syndrome International (DSi) is an international charity, comprised of memberships from individuals and organisations from all over the World. Members include people with Down syndrome, parents, family members, friends, caregivers, professionals, practitioners, researchers, organisations and more. DSi’s mission is to improve quality of life for people with Down syndrome worldwide and promote their inherent right to be accepted and included as valued and equal members of their communities. DSi believes this can only be achieved through improved knowledge of the condition, sharing of information and resources, and good communication and co-operation throughout the global Down syndrome community. For more information: www.ds-int.org.
World Down Syndrome Day 2016

Down Syndrome International presents a global video journey promoting inclusion of people with Down syndrome. "My Friends, My Community" features interviews with children from around the world talking about their lives, friendships and aspirations.

Visit: youtube.com/user/dsiwdsd