



Café Scientifique

Mothers Speak Up!

**On Parenting Children with Disabilities:
Implications for Mom's Wellbeing
and Social Support**

Organized by: Office of Echo Chair in Women's Mental Health Research

Monday May 6, 2013 9:30am-1:30pm
Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Rd, Toronto, Ontario



Canadian Institutes
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Canada

CIHR CAFÉ SCIENTIFIQUE
PRESENTS

Science on tap

Quench your interest

Monday 6 May 2013, 9:30am - 1:30pm

The Conference Centre, Holland Bloorview Kids Rehabilitation Hospital

150 Kilgour Rd. Toronto, Ontario.

Light Lunch will be provided. Please **RSVP** to owhchair@yorku.ca

Please let us know if you require any dietary or other accommodations.

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Mothers Speak Up! On Parenting Children with Disabilities: Implications for Mom's Wellbeing and Social Support

Do immigrant mothers caring for children with disabilities have a voice in the kinds of social support that is made available to them? Mothers Speak Up! is a statement that suggests the voices of immigrant mothers have not been heard in public policy – this café offers an opportunity for immigrant mothers to voice their opinions, to listen to other immigrant mothers address key policy issues as well as to share in recent York University research on mothering children with disabilities.

Charmaine C. Williams

Associate Professor
University of Toronto

Gail Jones

Director
Kerry's Place Autism Services

**PANELISTS:
Sheila Jennings**

PhD Candidate
Osgoode Hall Law School

Yana Skybin

Participant

Sharon Smith

Participant

**Moderator:
Nazilla Khanlou**

Principal Investigator
Associate Professor
York University



CIHR IRSC

Canadian Institutes of Health Research
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www.cihr-irsc.gc.ca

www.yorku.ca/nkhanlou

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MOTHERS SPEAK UP!

W E L C O M E



NAZILLA KHANLOU
RN, PHD

Echo Chair, Women's Mental Health Research
Faculty of Health
Academic Lead, Lillian Wright Maternal Child Health
Scholars Program

Associate Professor, School of Nursing
York University

4700 Keele St.
Toronto, ON
Canada
M3J 1P3

Website: www.yorku.ca/nkhanlou/

The Mothers Project Team would like to extend a very warm welcome to all gathered today at this special event. The “Mothers Speak Up!” CIHR Café Scientifique is an open and collaborative space for dialogue on issues affecting moms of children with disabilities. We hope that the conversation stimulates ideas that promote advocacy through community involvement, networking between mothers, and enhanced linkages across service sectors.

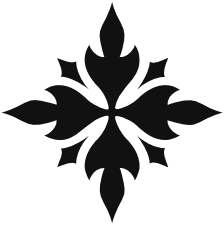
We are also very pleased to release today our study's information sheet on “Voices of Immigrant Mothers of Children with Disabilities: Availability and Use of Social Support.” The study looked at perceptions of social support among immigrant mothers of children with disabilities. Thirty immigrant mothers and 27 service providers were interviewed to determine what facilitates, or is a barrier to, support.

I am grateful to be supported by an amazing team in preparing for today! I sincerely thank panel members and project team members for all of their contributions (please see their biographies provided in this booklet). My particular gratitude to Wajma Soroor for all of her help towards organizing today's event.

We are very grateful to the Canadian Institutes of Health Research (CIHR), and in particular CIHR's Institute of Gender and Health, for their funding of today's Café Scientifique.

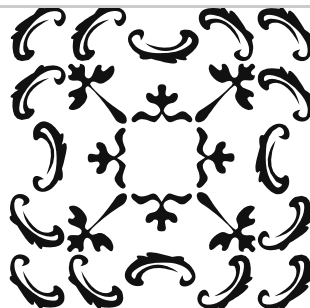
Finally, a special thank you to all the mothers, services providers, and policy makers who believe today's dialogue is important and who joined us today. Together we can inform each other and work toward the best services that support mothers and their children with disabilities - as *all* children and mothers deserve the very best that society has to offer.

Nazilla Khanlou



AGENDA

9:30am	Participant Registration Refreshments	Main room
10:00am– 10:30am	Welcome Address & overview of The Mothers Project Nazilla Khanlou	Main room
10:30am-12:00pm	Panel Discussion Sheila Jennings, Gail Jones, Yana Skybin, Sharon Smith, Charmaine C. Williams	Main room
12:00pm-12:45pm	Open Discussion Mahdiah Faye Dastjerdi, Deborah Davidson	Main room
12:45pm-1:00pm	Wrap up, CIHR evaluation and final remarks Nazilla Khanlou	Main room
1:00pm-1:30pm	Lunch & networking	Main room



BIOGRAPHIES



SHEILA JENNINGS *Panelist*

Sheila Jennings, is a project coordinator and research assistant to the Echo Chair in Women's Mental Health Research, Dr. Nazilla Khanlou. She is a lawyer who holds a masters degree in Critical Disability Studies from York University. Sheila is currently in the PhD program at Osgoode Hall Law School pursuing graduate research looking into the rights of mothers and their children with severe disabilities to support.

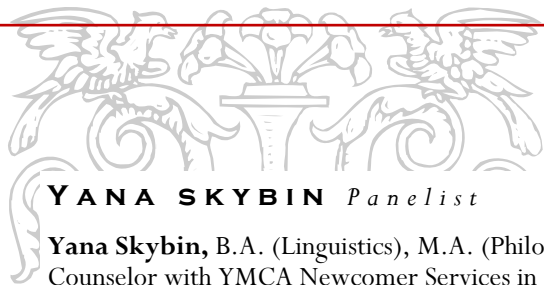
GAIL JONES *Panelist*

Gail Jones, is a Director of Community Support at Kerry's Place Autism Services - Central West Region. Gail has worked with children with disabilities and their families for over 30 years and attributes her greatest learning as having come from walking beside families.



NAZILLA KHANLOU *Moderator*

Nazilla Khanlou, RN, PhD, is Echo's inaugural Chair in Women's Mental Health Research in the Faculty of Health at York University and an Associate Professor in its School of Nursing. Professor Khanlou's clinical background is in psychiatric nursing. Her overall program of research is situated in the interdisciplinary field of community-based mental health promotion in general, and mental health promotion among youth and women in multicultural and immigrant-receiving settings in particular. She has received grants from peer-reviewed federal and provincial research funding agencies. Dr. Khanlou is the Academic Lead for the Lillian Wright Maternal Child Health Scholars program. She is founder of the International Network on Youth Integration (INYI), an international network for knowledge exchange and collaboration on youth. She has published articles, books, and reports on immigrant youth and women, and mental health. She is involved in knowledge translation to the public through media.



BIOGRAPHIES

YANA SKYBIN *Panelist*

Yana Skybin, B.A. (Linguistics), M.A. (Philosophy) lives in Barrie and currently works as a Settlement Counselor with YMCA Newcomer Services in Simcoe County. She immigrated to Canada in 2000 from Ukraine and has three children with various degree of autism, ages 8, 10 and 12. Ms. Skybin is an advocate and a member of Integration and Action for Inclusion (Simcoe Chapter).

"There were many appointments and a lot of chaos and sorrow in my life. I had to learn how the system works and not only learn how to navigate it, but also how to advocate on behalf of my daughter and help her at the same time. A year later my son was diagnosed with autism, and in another year the baby I was carrying was diagnosed with the same condition at the Autism Research Unit at Sick Kids' Hospital. I was now a mother of 3 children with autism and they all needed help. When my children were 3, 5 and 7 their father left, and I followed the path of so many other women who have children with special needs - singlehood. I did not give up, and found a job (I was home for 3 years at the time). My children are doing really well and we've learned to live with autism and be considerate of the needs of others."



SHARON SMITH *Panelist*

Sharon Smith, immigrated from Trinidad in the early 1990's and is the mother of three young adults, one of whom has medical and developmental challenges and another with a learning disability. Sharon lives in East York with her husband and three children.

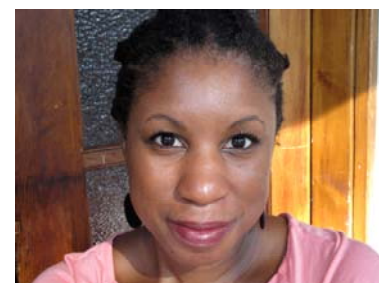
"I wouldn't have grown in the same way as I have if it weren't for the experience of working with these three interesting young people. I am grateful for the experience of being their mother."

The more I work with my son with complex needs the more I realize the need for more inclusive spaces. Although difficult, inclusion, in the long run, is the way to go."



CHARMAINE C. WILLIAMS *Panelist*

Charmaine C. Williams, MSW, PhD, RSW, is the Associate Dean Academic of Social Work and the Factor-Inwentash Chair in Social Work in Health and Mental Health. Her research bridges practice and access and equity issues that affect access to primary health care for racial minority women, HIV prevention in the Black communities, and individual and family experience of living with serious and persistent mental illnesses. The majority of her practice experience has been in the mental health care system where she worked in inpatient and outpatient services, providing interventions for individuals, families and groups. She has also been involved in organizational change initiatives in the health care sector, developing and delivering professional education in the areas of anti-racism, cultural competence, mental health and addictions, and addressing policy, procedural issues and complaints as the Anti-Racism officer for the University of Toronto.



MOTHERS PROJECT TEAM

Principal Investigator
NAZILLA KHANLOU

Project Coordinator
SHEILA JENNINGS

Please see www.yorku.ca/nkhanlou/community-based-research.html for a full list of the entire team.



SADORA ASEFEW

Sadora Asefew, is a volunteer for Echo Chair in Women's Mental Health Research. She is in the International Development Studies Program. Sadora's area of interest include the delivery of culturally sensitive programs and services to families and people in the disability community, the overrepresentation of racialized children in special education classrooms and how professional organizations can track outcomes for people with disabilities of diverse backgrounds as a tool to make meaningful changes in policies, resources and services delivery. Sadora brings with her over 6 years of hands-on experience in working in the disabilities field.

ALEXIS BUETTGEN

Alexis Buettgen, BA Hons., MA, is an affiliate of the Echo Chair in Women's Mental Health Research in the Faculty of Health at York University. She is currently a doctoral student in the Critical Disability Studies program at York University where she is interested in bridging the gap between academic knowledge and community action by contributing to emerging research that promotes transformative change in poverty reduction, human rights and international development. Most of Alexis' research and academic career has been influenced by her community involvement and passion for social justice. Her community involvement includes more than 10 years experience working and volunteering with several marginalized population groups including people with disabilities and other complex needs.



MAHDIEH FAYE DASTJERDI

Mahdieh Faye Dastjerdi, RN, PhD is a nurse, teacher, researcher and an immigrant. Dr. Dastjerdi's research deals with Iranian immigrant communities in particular and immigrants in general. Her research focus is on immigrant/refugee populations. In her PhD thesis (2007), she used grounded theory to examine Iranian immigrants' access to Canadian health care services. Although the focus of her doctoral study was on Iranian immigrants' experiences in accessing Canadian health care services, she has also had the opportunity to be involved in several different studies related to low-income, and immigrant family care givers as well as examining culturally appropriate assessment practices in an Early Childhood Development (ECD) project. She did her postdoctoral fellowship at International Institute for Qualitative Methodology (IIQM) in Alberta. Since 2008, as an assistant professor at York University, besides teaching, she is actively involved with different research projects as a primarily investigator (PI) or Co-I. Presently, Dr. Dastjerdi is conducting research on the quality of life of Iranian seniors living in GTA.

DEBORAH DAVIDSON

Deborah Davidson, PhD, Assistant Professor, is a sociologist and a mother bereaved by perinatal loss. Her work is focused in the areas of health, motherhood, and diversity. Methodologically, Dr. Davidson has expertise in qualitative methods and methodologies, and is particularly adept in researching sensitive topics with vulnerable populations. Her community volunteer work is with Bereaved Families of Ontario, where she has served on the Provincial Board, is Chair of the Professional Advisory Committee for Halton-Peel, and participates as peer facilitator and as a facilitation trainer.



MOTHERS PROJECT TEAM



NASIM HAQUE

Nasim Haque, MD, DrPH, has extensive experience in participatory research using both quantitative and qualitative methods. Dr. Haque received her doctoral degree from Johns Hopkins Bloomberg School of Public Health with an emphasis in reproductive epidemiology. Her focus in public health has been on maternal and child health, research methodologies and more recently on health systems strengthening and the social determinants of health as related to health equity. She has received research grants from CIHR to address complex issues of immigrant health and wellbeing in Toronto.

Dr. Haque is an Adjunct Assistant Professor at Bloomberg's School of Nursing, University of Toronto and a research associate with the Echo Chair Office at the Faculty of Health, York University. She is an independent public health specialist and works as a senior health consultant for UN organizations at the international level. She also serves as a member for The Toronto Public Health Ethics Committee and is a review committee member at The World Health Organization, Geneva.

JUDE NZUONKWELLE

Jude Nzuonkwelle, BScN, RN is a graduate assistant for the Echo Chair in Women's Mental Health Research held staff nurse positions in psychiatry and community health nursing, has been a clinical educator, nurse case manager, and undergraduate student preceptor. He has developed particular expertise in best practices related to working with marginalized populations and clinical management of clients in crises and emergency. Jude is also currently involved in the Best Practice Spotlight Organization initiative as a working group co-lead for the Best Practice Guideline: Assessment and Care of Adults at Risk of Suicide.



MEGHAN SAARI

Meghan Saari, BScN, RN, is a graduate assistant for the Echo Chair in Women's Mental Health Research. Meghan is currently enrolled in the Primary Health Care Nurse Practitioner (PHCNP) program at York University and has been working as an emergency nurse. She has obtained many certificates since her BScN including Coronary Care I, Coronary Care II, and the Trauma Nursing Core Course.

WAJMA SOROOR

Wajma Soroor, BA Hons., is a research assistant for the Echo Chair in Women's Mental Health Research in the Faculty of Health at York University. She is an Afghan born Canadian multimedia artist with experiences in stage, film, radio and TV. After working in the corporate communications sector, Wajma returned to school to earn a double major honors degree in Communications and Sociology at York University. Wajma's upbringing and experiences have led to her passion for advocacy for immigrant and refugee populations with a special interest in the health of women and families. To these ends, Wajma is currently studying nursing in York University's second entry program. She serves on the board of the Afghan Women's Organization, the largest settlement organization of its kind, and is grounded in Sociology, Communications and Nursing with an orientation to health equity and justice informed by the social determinants of health.



RESOURCES

FOR CHILDREN AND THEIR FAMILIES

Please note, this is not an all inclusive list and there are other resources which due to space limitations are not listed.

RESPITE SERVICES

COMMUNITY HELPERS FOR ACTIVE PARTICIPATION PROGRAM (CHAP)

.....416-422-7045

The CHAP program is a registry of people who are willing to support individuals who have autism/P.D.D. There is no charge for the use of the CHAP registry.

Website: <http://www.respiteservices.com/Toronto/index.aspx?CategoryID=14&lang=en-CA>

WWW.RESPITESERVICES.COM

.....416-325-0625 or 416-325-0623

Respiteservices is a group of agencies and is funded by the Ministry of Community and Social Services and the Ministry of Health. Respiteservices.com is part of the Toronto Developmental Services Network. Respiteservices.com has a respite facilitator and respite coordinator who act as respite information resources to agencies supporting families.

HEALTH AND OTHER SERVICES

ERINOAKKIDS

.....905-855-2690

ErinoakKids provides a comprehensive range of family-centred treatment, rehabilitation and support services to children with disabilities and their families who reside in Dufferin, Halton, Peel, Waterloo and Wellington.

Website: www.erinoakkids.ca

GENEVA CENTRE FOR AUTISM

.....416-322-7877

The Geneva Centre for Autism provides leadership in the development of services and raises awareness about autism.

Website: www.autism.net

Email: info@autism.net

HINCKS - DELLCREST CENTRE

.....416-972-1935

A non-profit children's mental health centre offering a comprehensive range of innovative mental health services to infants, children, youth, and their families.

Website: www.hincksdellcrest.com

Email: info@hincksdellcrest.org

KERRY'S PLACE AUTISM SERVICES

.....416-537-2000

Kerry's Place Autism Services provides community outreach services, psychological and family support services to people with an ASD and accommodation supports.

Website: www.kerrysplace.org

Email: info@kerrysplace.org

Interpretation services also offered, please see interpreter services for more.

ACCESS ALLIANCE

.....416-324-8677

Access Alliance works to promote health and well-being and improve access to services for immigrants and refugees in Toronto by addressing medical, social, economic and environmental issues.

Website: www.accessalliance.ca

Email: mail@accessalliance.ca

RESOURCES

FOR CHILDREN AND THEIR FAMILIES

HOLLAND BLOORVIEW CHILDREN'S REHABILITATION HOSPITAL

.....416-425-6220

Canada's largest children's rehabilitation hospital. Programs and services offered includes inpatient, outpatient as well as day patient services. Programs groupings are in rehab, complex continuing care, child development, and participation and inclusion.

DISTRESS CENTRES

.....416-408-4357 (HELP)

A free and confidential service available 24 hours a day offering emotional support, crisis intervention, and linkages to emergency help when necessary.

MENTAL HEALTH

ACROSS BOUNDARIES

.....416-787-3007

"*Across Boundaries* is a mental health centre that provides a range of support and services to people of color in the Greater Toronto Area who are experiencing severe mental health problems/serious mental illness."

Website: www.acrossboundaries.ca/

Email: info@acrossboundaries.ca

CENTRE FOR ADDICTION AND MENTAL HEALTH (CAMH)

.....416-535-8501

"*CAMH* is Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centres in the area of addiction and mental health."

Website: www.camh.ca

Email: info@camh.net

MENTAL HEALTH HELPLINE

.....1-866-531-2600

"The Mental Health Helpline provides information about mental health services in Ontario. We are funded by the Government of Ontario. Our service is live answer 24/7, confidential and free."

CITY/PROVINCIAL PROGRAMS

MINISTRY OF CHILDREN AND YOUTH SERVICES

"In 2003, the Ministry of Children and Youth Services was created to make it easier for families to find the services to give kids the best start in life, and to make it easier for families to access the services they need at all stages of a child's development and help youth become productive adults."

Website: www.children.gov.on.ca

Website: www.mhsio.on.ca

RESOURCES

FOR CHILDREN AND THEIR FAMILIES

ABA THERAPY FOR AUTISM

.....416-325-0500

Receive free health services information in Ontario 24 hours a day, 7 days a week, 365 days a year. All information provided is confidential and anonymous.

Website: www.mhsio.on.ca

GOVERNMENT FUNDING PROGRAMS

ASSISTANCE FOR CHILDREN WITH SEVERE DISABILITIES (ACSD)

.....416-325-0500

“If you are a parent caring for a child with a severe disability, you may be able to receive some financial help. The Assistance for Children with Severe Disabilities Program helps parents with some of the extra costs of caring for a child who has a severe disability.”

Website: www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx

ENHANCED RESPITE FOR CHILDREN WHO ARE MEDICALLY FRAGILE

.....416-325-0500

“Enhanced Respite for Children who are Medically Fragile and/or Technology Dependent (Enhanced Respite) is a grant paid to eligible families who are caring for a child at home who is medically fragile and/or technology dependent. The Ministry of Children and Youth Services (MCYS) is responsible for the provision of funding and policies related to Enhanced Respite, including the criteria used by the Community Care Access Centre (CCAC) to determine eligibility for funding.”

Website: www.health.gov.on.ca/english/providers/pub/manuals/ccac/cspm_sec_3/3-11.html

SPECIAL SERVICES AT HOME (SSAH)

.....416-325-0500

“The Special Services at Home program helps families who are caring for a child with a developmental or physical disability. It is funded and managed by the Ministry of Community and Social Services. The program helps families pay for special services in or outside the family home as long as the child is not receiving support from a residential program.”

Website: www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx

CITY OF TORONTO: Services for Children with Special Needs

.....416-392-2489 or 416-338-0889 or 311

Children's Services provides enhanced services to child care programs so that every child who needs extra support can actively participate in the program.

Website: www.toronto.ca/children/specialneeds

Email: 311@toronto.ca

RESOURCES

FOR CHILDREN AND THEIR FAMILIES

FINANCIAL RESOURCES

FINANCIAL TIPS FOR PARTS OF CHILDREN WITH SPECIAL NEEDS416-482-8255

“Children and youth with special needs have medical, emotional, developmental, mental or behavioral problems that require ongoing help and support. Ontario has a number of provincial programs to help families and caregivers of children and youth with special needs. The federal government also offers tax deductions. This page (and the downloadable document you find here) will outline the main sources of financial help.”

Website: www.cheo.on.ca/en/financialtipsspecialneeds

LEGAL SERVICES

ARCH DISABILITY LAW CENTRE416-482-8255

ARCH provides a range of legal services to people with disabilities who live in Ontario, disability advocacy organizations, and the legal profession.

Website: www.archdisabilitylaw.ca
Email: archlib@lao.on.ca

THE CHILD ADVOCACY PROJECT416-977-4448 ext 230

The Child Advocacy Project (CAP) is dedicated to enhancing access to justice for children by providing free legal services to low income families who cannot afford a lawyer.

Website: www.childadvocacy.ca
Email: info@childadvocacy.ca

JUSTICE FOR CHILDREN AND YOUTH416-920-1633

A legal clinic providing direct legal assistance in all areas of children's law to eligible young people in Toronto and vicinity.

Website: www.jfcy.org
Email: info@jfcy.org

PROVINCIAL CHILD ADVOCATE416-482-4103

The Office of the Provincial Advocate for Children and Youth serves youth in state care and the margins of state care through individual, systemic and policy advocacy.

Website: www.provincialadvocate.on.ca
Email: advocacy@provincialadvocate.on.ca

RESOURCES

FOR CHILDREN AND THEIR FAMILIES

IMMIGRATION SERVICES

DIXIE BLOOR NEIGHBOURHOOD SERVICES905-629-1873

The Disability Settlement Service provides information, referrals, support and advocacy to help individuals living with any kind of disability.

Website: www.dbncentre.com

Email: info@dixiebloor.ca

REXDALE WOMEN'S CENTRE416-745-0062

Provides services for those with high-needs in Etobicoke.

Website: www.rexdalewomen.org

Email: office@rexdalewomen.org

ORGANIZATIONS

AUTISM ONTARIO416-246-9592
www.autismontario.com

CANADIAN MENTAL HEALTH ASSOCIATION416-789-7957
www.toronto.cmha.ca

CANADIAN ASSOCIATION FOR THE DEAF613-565-2882
www.cad.ca

DEVELOPMENTAL SERVICES OF ONTARIO1-855-372-3858
www.dsontario.ca

ETHNORACIAL PEOPLE WITH DISABILITIES COALITION OF ONTARIO416-901-5454
www.erdco.ca

INDEPENDENT LIVING CANADA613-569-2581
www.ilcanada.ca

PEOPLE FIRST OF CANADA204-784-7362

MOTHER'S SPEAK UP!

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