



International Association for the Scientific Study of Intellectual and Developmental Disabilities

Parenting with Intellectual Disabilities

Special Interest Research Group Newsletter

INTRODUCTION

Hello to all our Parents and Parenting with IDD SIRG members,

We hope you have been able to stay safe and creative in negotiating all the changes that the World's pandemic has brought on! Staying connected with everyone can be a challenge in those times. Our aim is to stay connected with you via this newsletter and social media posts!

After having had to cancel the Hyderabad Conference, we are happy to share with you the 2021 Amsterdam Conference will occur on a Hybrid format. This means that symposia, roundtables and keynotes will be offered online, with some offered in person. Check out more information at: <https://www.iassidd2021.com/>. As we get closer to the date, we will be able to offer you more details! In the meantime, the Call for papers has been announced and is open **until December 15th 2020**. The conference theme is Celebrating Differences, a theme meant to value diversity. To help with the organisation of the conference, four tracks are offered. When submitting abstracts, you will be asked to determine under which track your presentation fits. The four tracks are: (1) IDD across the lifespan, (2) Quality of Life and support, (3) Health, Behavior and disability conditions, (4) Ethics, Politics and Diversity. It was suggested that presentations under our SIRG be submitted under Track 2, Quality of Life and Support. Although our field of research could relate to all four tracks, we are asking that you submit under Track 2 AND that you identify in the title of your presentation that you are part of the Parenting SIRG. This will be easier for us to build symposia.

Our Parenting SIRG Executive met on November 2nd to discuss our objectives for the next couple of years. Three main objectives have emerged under one big purpose: to stay connected with you and other researchers, clinicians and self-advocates.

November 2020



Inside this issue:

Introduction	1
Membership news	2
Introduction of new team members	2
New publications and resources	5
What is happening around the World...	7
We need your help!	7



Parenting SIRG picture taken at the IASSIDD World Congress in Glasgow, Scotland (August 2019)



As such, two webinars will be offered to our community in 2021, one in April and the other in October. The first webinar will focus on health disparities in women with IDD and their children, and will be co-sponsored by the National Research Center for Parents with Disabilities at the Lurie Institute for Disability Policy (under Monika Mitra), the IASSIDD Academy and the Parenting, Health and Ethics SIRGs (For more information: www.centerforparentswithdisabilities.org). The second webinar will focus on Systemic Discrimination and will be co-sponsored by the University of Minnesota (under Traci Laliberte), the IASSIDD Academy, the Parenting and Ethics SIRGs. As a second objective, we will review our social media strategy and finally our third will be to ensure representation of our topic of research at the European Congress in Amsterdam in July 2021. We look forward to the privilege of physically reuniting!

SAVE THE DATE!

6th IASSIDD Europe
Congress
Amsterdam
6 – 8 July 2021



Until then, to help our community grow, please inform people of our webpage via IASSIDD, our Facebook page, and our newsletters. We want to connect with researchers in the field and stay connected as a SIRG. The aim is to keep informed of what is done internationally to support and understand the realities of parents and families headed by persons with intellectual disabilities!

Sincerely,
The Executive

MEMBERSHIP NEWS

2021 is right around the corner! Please indicate in your agendas to renew your membership. Go to iassidd.org and click on Update Membership, or on Membership in the main menu. When you renew, please strongly consider selecting Parenting as your primary SIRG.

PRESENTATION OF NEWS MEMBERS

We have few colleagues to present in this newsletter. Profiles of members will be shared on our social media platform in the future. Make sure you don't miss out, and like our facebook page (<https://www.facebook.com/iassiddparentingsirg>) and Instagram account (@IASSIDDParentingSIRG).

Joany Tremblay

Joany Tremblay is a master candidate in Psychoeducation at Université de Montréal, in Montreal, Canada. She is supervised by Dr. Marc J. Lanovaz, Ph. D., Ps.Ed.. For her project, she will replicate the Master thesis of Munazza Tahir's to verify the effectiveness of a skill-based parenting intervention *The Family Game*. This program is designed by Dr. Maurice Feldman to teach parents with intellectual disabilities to increase positive rapport with their children and to use noncorporal positive-based child behaviour management strategies.

The study of Munazza Tahir's showed positive results in improving the parenting skills with two mothers with intellectual disabilities. Joany wants to replicate this study in order to

check if we can obtain the same results and to increase evidence of the effectiveness of this program. More precisely, she will test with a multiple baseline design if there is an improvement in three parental skills: delivering clear instructions, reinforcing the child compliance behaviours and correction of child noncompliance. Also, she will test if there are reductions in child noncompliance and problem behaviours.

Joany has a bachelor's degree in Psychoeducation and a certificate in intervention in intellectual disability and autism. She is a research assistant at the Applied Behavioral Research Lab and she worked on different projects, covering autism and intellectual disabilities. She has now discovered an area of interest in parenting of people with intellectual disabilities, as well as challenging behaviours in children, and she looks forward to continuing to contribute knowledge on this subject.

For more information: joany.tremblay@umontreal.ca

Constance Remhof

Constance Remhof is Masters student in education and social work at Universität Siegen in NRW, Germany. Since 2018, she is working as a Project Assistant together with Prof. Dr. Albrecht Rohrmann and Miriam Düber as scientific support in the project "*Entwicklung von Leitlinien zu Qualitätsmerkmalen Begleiteter Elternschaft in Nordrhein-Westfalen*" which is a research project to develop guidelines on quality features of support for parents with intellectual disabilities (<https://www.mobile-dortmund.de/141-o-Modellprojekt-Begleitete-Elternschaft-NRW.html>).

Within the project, the researchers have, among other things, also surveyed the perspective of meanwhile adult children of parents with intellectual disabilities. The first findings were so exciting that Constance plan to pursue this topic next year in the course of a doctorate. In addition to her work as a project assistant, she has been working as a tutor and peer-teacher in the field of methods of empirical social research since 2017, which has strengthened her interest in research.

Within the project, she also wrote her bachelor thesis on the perspective of professionals who support parents with intellectual disabilities on an outpatient basis. This was published as a book at the beginning of this year:

Remhof, C. (2020). Anforderungen an die Begleitung von Eltern mit Lernschwierigkeiten und ihren Kindern in der Wahrnehmung von pädagogischen Fachkräften, Siegen: universi Universitätsverlag Siegen.

Constance also contributed to two papers on results from group discussions and interviews with parents within the project.

Düber, Miriam & Remhof, Constance (2018). Ergebnisse der Gruppendiskussionen. Bericht im Rahmen des Modellprojektes „Entwicklung von Leitlinien zu Qualitätsmerkmalen Begleiteter Elternschaft in Nordrhein-Westfalen“, hrsg. von MOBILE Selbstbestimmtes Leben Behinderter e.V.

Joany Tremblay



How to renew your MEMBERSHIP?

Visit iassidd.org and click on Update Membership, or on Membership in the main menu.

Remember...

For each member registration that selects the Parenting SIRG as its Primary SIRG, the SIRG is allocated 20\$ in their budget. These funds can then be used to offer travel grants to our students, for example.



Constance Remhof



Dr. Nicole Brisson



Publication by Dr. Brisson:

Brisson, N. (2017). Determining the Parenting Capacity of Parents with Low IQ. *Juvenile Law Reader*, 14(3), 1, 3-6.



**International Association for
the Scientific Study of Intellectual
and Developmental Disabilities**

Link: https://www.mobile-dortmund.de/files/auswertung_gruppendiskussionen.pdf

Düber, Miriam; Koch, Anna; Remhof, Constance; Riesberg, Ulla; Sprung, Christiane (2018): Ergebnisse der Interviews mit den Eltern. Bericht im Rahmen des Modellprojektes „Entwicklung von Leitlinien zu Qualitätsmerkmalen Begleiteter Elternschaft in Nordrhein-Westfalen“, hrsg. von MOBILE Selbstbestimmtes Leben Behinderter e.V.

Link: https://www.mobile-dortmund.de/files/ergebnisse_elterninterviews.pdf

For more information: constanceremhof@gmail.com

Dr. Nicole Brisson

Dr. Brisson is a clinician-researcher. She is the Owner and Director of Sage Haven Associates, Inc., a private practice specializing in meeting the needs of parents with intellectual and developmental disabilities (IDD). She has been recognized as a national expert in providing competence-based parenting assessments to parents with IDD by the United States Departments of Justice and Health and Human Services. She and her multidisciplinary team provide parenting assessments, training, parent education, and consultation regarding parents with IDD across the United States. In addition, Dr. Brisson developed and taught a graduate-level course on child welfare and parental disability at the University of Vermont.

Dr. Brisson is the creator of the SAGE Family Assessment Model-Inventory (SFAM-I), a measure to evaluate parenting skills and assist child welfare agencies in making accommodations that empower parents with IDD and give them a fair chance to parent. Dr. Brisson is in the early stages of researching the efficacy of this tool. She is also the creator of the CARE to Parent curriculum, an interactive parenting skills curriculum for parents with IDD. Her preliminary research found some positive results and she hopes to expand the curriculum in the future.

Dr. Brisson was awarded the Carrie Ann Lucas Disability Rights Legal Advocate Award for her vision, dedication, advocacy, and leadership work in systems change and advancement of best practices in the legal system for parents with disabilities. She is a Fellow of the American Association on Intellectual and Developmental Disabilities and the Vice President of The Association for Successful Parenting, an international organization committed to enhancing the lives of families when parents have learning difficulties.

For more information: sagehaven@gmail.com

Dr. Wendy Zeitlin

Dr. Wendy Zeitlin is an Assistant Professor in the Department of Social Work and Child Advocacy at Montclair State University. Her scholarship throughout her career has focused on overall child wellbeing with an emphasis on disabilities and child welfare.

Wendy's research has always been guided by practical applicability of research findings with a particular emphasis on underserved populations. For the past several years, she has collaborated with Dr. Astraea Augsberger at Boston University's School of Social Work and staff at the Westchester Institute for Human Development to evaluate Project IMPACT, a home-based maltreatment prevention program designed for parents with intellectual disability whose children are at risk for removal. Based on this work, Wendy came to the conclusion that the dearth of research in this field has important social justice implications that can and should be addressed. She hopes that her interest and research expertise can help move the field forward in important ways in the coming years.

Currently, she is continuing her collaboration with Dr. Augsberger and others to understand decision-making in child welfare when parents have intellectual disabilities. It is the hope that this ongoing work can influence child welfare practice and policy to better serve children and families.

For more information: zeitlinw@montclair.edu

NEW PUBLICATIONS AND RESOURCES

Akobirshoev, I., Mitra, M., Parish, S., Valentine, A. & Moore Simas, T. (2020) Racial and ethnic disparities in birth outcomes and labor and delivery charges among Massachusetts women with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 58(2), 126-138. doi:10.1352/1934-9556-58.2.126

Aunos, M. & Feldman, M. (2020). Parenting by persons with developmental disabilities. In I. Brown, M. Percy, H. M. Aldersey, R. A. Condillac, W. L. A. Fung, & B. J. Isaacs (Editors). *Developmental Disabilities in Ontario* (4th edition). Chapter 49: Parenting by persons with Developmental Disabilities. Toronto, ON: Delphi Graphic Communications.

Bernoldová, J., Strnadová, I., & Adamčíková, Z. (2019). *Women with intellectual disabilities in the role of mothers* [In Czech: *Ženy s mentálním postižením v roli matek*]. Praha: Karolinum a Nakladatelství Pedagogické Fakulty.

Clements, K. M., Mitra, M., Zhang, J. & Parish, S. L. (2020). Postpartum outpatient health care utilization among women with and without intellectual and developmental disabilities. *American Journal of Preventive Medicine*, 59(3), 437-444. doi: 10.1016/j.amepre.2020.03.011

Collings, S. & Spencer, M. (2020). *Mums with an intellectual disability already risk family violence and losing their kids: Coronavirus could make things worse*. Link: <https://theconversation.com/mums-with-an-intellectual-disability-already-risk-family-violence-and-losing-their-kids-coronavirus-could-make-things-worse-131468>

Collings, S. & Spencer, M. (2020). *Practices that support parenting by parents with intellectual disability*. Link: <https://aifs.gov.au/cfca/2020/09/30/practices-support-parenting-parents-intellectual-disability>

Dr. Wendy Zeitlin



Publication by Dr. Zeitlin:

Augsberger, A., Zeitlin, W., Rao, T., Weisberg, D., & Toraif, N. (in press). Examining a child welfare parenting intervention for parents with intellectual disabilities. *Research on Social Work Practice*. doi:10.1177/1049731520958489

Zeitlin, W., Augsberger, A., Rao, T., Weisberg, D., & Toraif, N. (2020). Measuring Parenting Skills: Validating the Skills Assessment for Parents with Intellectual Disability. *Journal of Evidence-Based Social Work*, 1-14.

[doi:10.1080/26408066.2020.1830909](https://doi.org/10.1080/26408066.2020.1830909)



International Association for the Scientific Study
of Intellectual and Developmental Disabilities



DeZelar, S. & Lightfoot, E. (2020). Who refers parents with intellectual disabilities to the child welfare system? An analysis of referral sources and substantiation. *Children and Youth Services Review*, 119. doi:10.1016/j.chidyouth.2020.105639

Feldman, M. A. & Aunos, M. (2020). Recent Trends and Future Directions in Research Regarding Parents with Intellectual and Developmental Disabilities. *Current Developmental Disorders Reports*, 7, 173–181. doi: 10.1007/s40474-020-00204-y

McConnell, D. et al. (2020). *Male Partner Violence Against Women with Cognitive Disabilities: General guidance for community outreach workers*. University of Alberta: Canada.

Powell, R.M., Parish, S.L., Mitra, M. & Rosenthal, E. (2019). Role of family caregivers regarding sexual and reproductive health for women and girls with intellectual disability: A scoping review. *Journal of Intellectual Disability Research*. doi:10.1111/jir.12706.

IASSIDD Academy library

We need your help!

Submit your resources to

Marjorie Aunos

ninja.marj@gmail.com

Retzer, A., Kaye, J., & Gray, R. (2020). A factorial survey investigating the effect of disclosing parental intellectual disability on risk assessments by children's social workers in child safeguarding scenarios. *The British Journal of Social Work*, 50(4), 1185–1200.

The IDD Women's Study: For Providers. Link: <https://heller.brandeis.edu/parents-with-disabilities/info-resources-research-briefs/health-mental-health-healthcare/idd-womens-study-providers.html>

Zeitlin, W., Augsberger, A., Rao, T., Weisberg, D. & Toraif, N. (2020). Measuring Parenting Skills: Validating the Skills Assessment for Parents with Intellectual Disability. *Journal of Evidence-Based Social Work*. doi:10.1080/26408066.2020.1830909

The IASSIDD Academy is trying to build a library of good training, validated resources to post on the IASSIDD website. There is now a section under the Academy, Training Resources that highlight training resources (<https://www.iassidd.org/academy-training-resources/>). Those resources could also be presented under our SIRG with a link to the Academy page.

We need **YOUR HELP** to nominate useful and scholarly credible training resources that could be posted. Please send your submissions to Marjorie Aunos, so she can relay them on behalf of our SIRG. As this list of training resources is on ongoing project, please ensure to inform us when you develop new training resources.



WHAT IS HAPPENING AROUND THE WORLD...

If you have any current project you are currently working on and would like to share with us, please send us an email!

YOU are important to the SIRG: continue to inform us of your achievements and successes!

Anything new in research or clinical practice in your area? Please let us know!

THANK YOU!

An a BIG thank you to Annie-Claude Villeneuve for editing the newsletter for us!

Your SIRG Executive: Margaret Spencer, Susan Collings, Traci Laliberte, David McConnell, Monika Mitra, Marja Hodes, Hilary Brown, Iva Strnadová, Carmit-Noa Shpigelman, Lynne Potvin and Marjorie Aunos

CONTACT INFORMATION:

Margaret Spencer (margaret.spencer@sydney.edu.au)

Susan Collings (susan.collings@sydney.edu.au)

Traci Laliberte (lalio017@umn.edu)

David McConnell (david4@ualberta.ca)

Iva Strnadová (i.strnadova@unsw.edu.au)

Monika Mitra (mmitra@brandeis.edu)

Marja Hodes (mhodes@asvz.nl)

Hilary Brown (hk.brown@utoronto.ca)

Lynne Potvin (lpotvio1@uottawa.ca)

Carmit-Noa Shpigelman (carmits@univ.haifa.ac.il)

Marjorie Aunos (ninja.marj@gmail.com)

If you have any current project you are currently working on and would like to share with us, please send us an email!



HYBRID

6th IASSIDD

Europe congress Value Diversity

AMSTERDAM 6 - 8 JULY 2021

