



International Association for the Scientific Study of
Intellectual and Developmental Disabilities
Parenting with Intellectual Disabilities
Special Interest Research Group Newsletter

Happy 2018 to everyone! May we all have good health and great successes in our grant proposals and research studies!

This newsletter, the first of 2018, is meant to relay information about last IASSIDD Congress in Bangkok and the upcoming one in Athens. Furthermore, we took the opportunity to introduce two new Parenting SIRG members, a new student in the field and the arrival of an 'old' friend. Welcome (or welcome back) to all of them!

4th Asia Pacific IASSIDD Conference Nov 2017

Margaret Spencer, Parenting SIRG Committee Member and Social Work Lecturer at University of Sydney, brings home news from the conference:

In November, the Fourth Asia Pacific IASSIDD Conference was held in Bangkok. The parenting SIRG convened a symposium. Three of the four papers presented in this symposium related to parents with intellectual disabilities in the child protection system. Maurice Feldman presented research undertaken with David McConnell, Marjorie Aunos and Laura Pacheco, on the prevalence of child protection outcomes in families led by parents with cognitive impairment in Canada. I presented two papers based on findings from an evaluation study undertaken with Susan Collings, Angela Dew, Erin Cooney and Leanne Dowse (University of New South Wales) on a specialist advocacy program for parents with intellectual disabilities involved in child protection investigations and care proceedings in New South Wales, Australia. One paper reported on domestic violence, mothering and child protection and the other on the viability of using volunteers to support parents with intellectual disabilities involved in care proceedings.

All three papers highlighted we still have a long way to go to ensure parents with intellectual disabilities are well set up for parenthood, supported and treated fairly. To this end, the fourth paper, presented by Patsie Frawley from Deakin University Australia, reported on a peer education program about sexual rights and sexual wellbeing, which she proposed has among its goals fostering positive pathways to parenthood for young adults with intellectual disabilities.



Winter 2018



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In addition to the symposium papers, Monica Mitra, from the US National Research Center for Parents with Disabilities at Brandis University, presented on emergency department use among mothers with intellectual disabilities with postpartum infants. And, while not specifically about parenthood, Ran Neuman and Shunit Reiter from Israel, presented a very interesting paper on establishing and maintaining couplehood as perceived by couples with intellectual disabilities.

Strong attendance and interest in these presentations, as well as in the preconference workshop on *Sexuality-Enabling Rights and Choices*, reflects a growing interest in the realisation of Article 23 of the UNCRPD particularly in the Asia-Pacific Region.

As is always the case at conferences, it is as much the sharing and networking that takes place outside of sessions that is so worthwhile. I had great discussions with Ran Neumann and Shunit Reiter (now members of our SIRG – welcome Ran and Shunit) about parenting with intellectual disability in Israel; as well as with Monica Mitra about projects underway at the US National Center for Parents with Disabilities and potential research topics related to parents with intellectual disability. It was good to meet Claire Azzopardi- Lane from the University of Malta who is a new member of our SIRG. Her Faculty, the Faculty of Social Wellbeing, are hosting the Euro-Mediterranean Conference on Disability Studies and Disability Activism 2-4 May 2018 and is eager for members of the SIRG to attend <https://www.um.edu.mt/events/ediz2018>. Also, as always lovely to reconnect and catch up with Emiko Nagaoka Tanaka, from Japan.



During the conference I attended, on behalf of Marjorie Aunos, a SIRG Chair Meeting. The message from the IASSIDD Executive is that each SIRG needs to be actively recruiting new members to retain SIRG status. Our SIRG is particularly vulnerable due to our small (albeit engaged and committed) membership. Also the word from the Executive is that SIRGS need to be generating income by hosting IASSIDD events such as regional seminars and webinars – something we maybe should be thinking about for 2018.

Lastly during the conference, SIRG members and other attendees floated (over evening drinks) whether it would be beneficial to broaden and reconstitute the parenting SIRG to encompass and reflect other components of UNCRPD Article 23. IASSIDD members with a research interest in sexual rights, wellbeing and relationships do not have their own SIRG and joining forces would firm up our SIRG membership base. The question is, would broadening our research focus have positive or detrimental impact on advancing the parents with intellectual disability research agenda? Is there sufficient synergy between our respective research interests to come together? I put these questions out to SIRG members for further consideration and discussion. Maybe it could be discussed further online or for those attending Athens in July over evening drinks!

Membership News

It is NOW time to renew your membership. Please click [here](#) to renew your IASSIDD membership and choose Parenting SIRG as your primary SIRG!

Remember, for each member registration where a member chooses a SIRG as its Primary SIRG, the SIRG gets 20\$ in their budget. This money can be used as travel grants, support for young professionals (as it was used in the past) or to support self-advocates to attend our conferences.

We are asking each of us to continue our efforts in making our SIRG known. Please inform people of our [webpage](#) via IASSIDD, our [Facebook page](#), and our newsletters. The more we are, the more fruitful collaborations we can explore, the more we all get informed of what is being done internationally to support and understand the realities of parents and families headed by persons with intellectual disabilities!

Effective Strategies for Working with Involuntary Clients: International Perspectives

Effective Strategies for Working with Involuntary Clients: International Perspectives

- Tuscany, Italy
- May 23-25 2017

This international conference on working with involuntary clients, gathering ideas from research, policy, and practice is about strategies for effective practice in child welfare, corrections, disability services, social welfare and family services, health/mental health substance use/abuse and domestic violence. In addition, presentations related to legal, ethical, and cultural are issues invited. Issues related to the dynamics of working with this population will be discussed, with an emphasis on the importance of building relationships, engagement and problem solving.

Registration now open!

Learn more at <https://casw.umn.edu/portfolios-items/pratoconference>

Click [here](#) to register now





IASSIDD Europe Congress

Diversity & Belonging:
Celebrating difference

- July 18 - 20, 2018 Athens, Greece

Diversity & Belonging is the theme of the 5th IASSIDD Europe Congress in Athens, Greece, July 18-20, 2018. This theme is a celebration of human diversity, within spaces and places where we feel 'at home'.

Early bird registration is available until April 15th

Click [here](#) to register now!

IASSIDD EUROPEAN AND WORLD CONFERENCE – ATHENS (2018) AND GLASGOW (2019):

650 abstracts were submitted for the European Congress in July 2018 in Athens. Sixteen of those were abstracts concerning the parenthood of people with ID! These abstracts bring forward different elements in regards to relationships, new technologies, new intervention approaches and strategies, community links in support of parents with ID, and analysed of system issues.

Registration to the Congress opens on February 1st – [Register Today!](#)

New Members to our Field and SIRG:

Beth Tarleton

Beth Tarleton has re-joined the IASSIDD Sirg. Beth has been working on positive support for parents with learning difficulties in the UK for over 10 years. (The term learning difficulties is used to include parents who have a diagnosed learning disability /intellectual disability and those with a milder impairment who struggle with similar issues and often don't get services in their own right.) In 2005, Beth and colleagues undertook a mapping study which investigated the issues in providing support for parents and how services were responding. The findings from this study fed into the 2007 English Good Practice Guidance on Working with Parents with a Learning Disability and continue to be referenced in high-level court cases in the UK. At this point, Beth set up the Working Together with Parents Network (WTPN) (www.wtpn.co.uk) which aims to support professionals working with parents with learning difficulties. Ten years after the initial publication of the Guidance, and following judicial criticism of the failure of

professionals to comply with its principles, the WTPN updated it and is working to raise awareness, particularly with Children's social workers, and with the legal sector. Free conference and training events are provided to share positive practice. The WTPN has about 900 members across England, Scotland and Wales and has specific countrywide networks in Wales and Scotland and 4 regional networks in England. Policy officers have been appointed to identify relevant laws, provide advice to practitioners and to influence policy at national and local level. During the intervening years, Beth has evaluated specialist advocacy for parents, a specialist support service and an adapted parenting programme for mothers with learning difficulties. Beth is currently leading some research which is looking into how good practice actually happens by looking in detail into how professionals worked together and with parents in cases which professionals view as 'successful'.

If you wish further information about Beth's research, please contact her:

beth.tarleton@bris.ac.uk

Ran Neuman

Dr. Neuman is a lecturer in the Department of Education and Department of Social Work, in Zefat Academic College, in Israel. He is also a member of the executive board of 'Kfar Tikva' - a rehabilitative community and home for people with disabilities, in Israel.

By binding academic activity and field work, Ran tries to strengthen the links between theory and practice, and thereby improve interventions and support systems available to people with ID. Recently he founded an Academic Center in Kfar Tikva, dedicated to conducting research and field studies related to adults with disabilities.

Shunit Reiter

Prof. Shunit Reiter is a professor Emerita of the Department of Special Education, The Faculty of Education, University of Haifa and a visiting professor in the Zefat Academic College, in Israel. Lately she joined the Academic Center founded by Dr. Ran Neuman in 'Kfar Tikva' - a rehabilitative community and home for people with disabilities, in Israel, where she is the academic advisor of the center.

For more than 40 years she has been involved in developing a theoretical framework for understanding people with disabilities first and foremost as human beings who are not different than other people except for the need to overcome difficulties arising out of their disabilities. Her special contribution can be found in the exposition of the Humanistic paradigm as the guidelines for programs in special education and for the supports provided

Ran focuses his research on couple Relationships of adults with ID, and is currently running a research study on the attitudes of service providers and families towards: couple-hood, sexuality and parenthood of people with ID.

In the coming years Ran hopes to develop programs that will enable adults with ID to identify their desires and wishes, choose their unique ways, and find the means to make their voices heard in order to achieve their goals.

If you wish further information about Ran's research, please contact him:
ran.no@zefat.ac.il

by human services to persons with disabilities and their families. This was developed in her books - Disability and Society (1999) and Disability from a Humanistic Perspective: Towards a better Quality of Life, (2008).

Among the numerous Ph.D. thesis she supervised some focused on different aspects of family relationships such as the significance of the Bar/bat mitzvah ceremony for parents of Jewish children with developmental disabilities, or the Role division and family support in the Arab society, as factors related to coping styles and anxiety level among mothers and fathers of children with mental disability, and Ran Neuman's Ph.D. research on couple relationships among adults with ID.

If you wish further information about Shunit's research, please contact her:
shunitr@edu.haifa.ac.il

Publications from Ran:

Neuman, R. & Reiter, S. (2017). [Couple relationships as perceived by people with intellectual disability -Implications for quality of life and self-concept](#). International Journal of Developmental Disabilities. 63(3), 138-147.

Neuman, R. & Reiter, S. (2015). The experience of couple relationships as reflected in the stories of people with intellectual and developmental disability. Journal of Israel Studies in Language and Society. A special issue on: Voices of people with disabilities in the Israeli society. 7(1-2) 200-217. (Hebrew).



Dr. Ran Neuman



**Prof. Shunit Reiter
(Emerita)**

**Publications from Shunit:**

Reiter, S. (2008). [Disability from a humanistic perspective: Towards a better quality of life.](#) New York: Nova Science Publishers Book Series: Health and Human Development.

Odeh, L., Reiter, S. (2011). Role division and family support in the Arab society, as a factor related to coping styles and anxiety level among mothers and fathers of children with mental disability. In: Meir Hovav and Benfamin Hozmi (Eds.) *From Inclusion towards Full Participation* (pages: 271 – 297). (Hebrew).



Annie-Claude Villeneuve

Annie-Claude Villeneuve

Annie-Claude Villeneuve is a Masters student in psychoeducation at Université du Québec à Trois-Rivières (UQTR), located in the province of Quebec, Canada. In 2012, as part of her collegial study, she produced a research report about the relationship between the history of social participation of people with intellectual disability and the growth of the number of parents with intellectual disability. This report has been the beginning of a growing interest about parenthood and intellectual disability.

Her curiosity about the use of technology to empower people with intellectual disability led her to contact Dany Lussier-Desrochers Ph.D., professor at the UQTR. Together, they designed an innovative pilot project about the effectiveness of technology support to enhance parenting skills of parents with intellectual disability.

Research to date has shown that technology not only promote independent living and self-determination of people with intellectual or developmental disability, but also contribute to learning new skills. On the other hand, few authors have studied how technology can meet the specific needs of mothers and fathers with intellectual disability, which is the main focus of Annie-Claude's research. This project will deepen a research area that is actually few documented, support specialized programs in intellectual disability in setting up adapted intervention for addressing parenthood and, ultimately, directly involve these parents in the choice and implementation of solutions to promote their social and digital participation.

If you wish further information about Annie-Claude's research, please contact her: annie-claude.villeneuve@uqtr.ca

New Publications and Resources:

We encourage you to check out the following new publications!

And do not forget to let us know when new studies are published in the field!

Collings, S., Dew, A., Gordon, T., Spencer, M., & Dowse, L. (2017). Intersectional Disadvantage: Exploring Differences Between Aboriginal and Non-Aboriginal Parents with Intellectual Disability in the New South Wales Child Protection System. *Journal of Public Child Welfare*, 1-20. <http://dx.doi.org/10.1080/15548732.2017.1379456>

Background: Parents with intellectual disability and Aboriginal and Torres Strait Islander parents are overrepresented in child removal but research has not explored the intersection of Aboriginality and intellectual disability in child protection. **Methods:** A case file review of 45 parents with intellectual disability (n = 14 Aboriginal and n = 31 non-Aboriginal) engaged in care proceedings in New South Wales was undertaken. Parent and child demographics and investigation triggers and outcomes were compared.

Results: Aboriginal parents were significantly younger than non-Aboriginal parents at initiation of an investigation, twice as likely to be investigated due to concerns about parenting capacity, and more likely to have children removed than non-Aboriginal parents. **Conclusion:** The intersection of Aboriginality and intellectual disability appears to increase the risk of negative encounters with child protection systems. Targeted support for young Aboriginal parents and greater disability awareness and cultural sensitivity by child welfare workers are needed.

Wall-Wieler, E., Roos, L. L., Brownell, M., Nickel, N. C., & Chateau, D. (2018). Predictors of having a first child taken into care at birth: a population-based retrospective cohort study. *Child abuse & neglect*, 76, 1-9. <https://doi.org/10.1016/j.chiabu.2017.09.033>

The objective of this study is to determine which maternal events and diagnoses in the two years before childbirth are associated with higher risk for having a first child taken into care at birth by child protection services. A population-based retrospective cohort of women whose first child was born in Manitoba, Canada between 2002 and 2012 and lived in the province at least two years before the birth of their first child (n = 53,565) was created using linkable administrative data. A logistic regression model determined the adjusted odds ratios (AOR) of having a child taken into care at birth. Characteristics having the strongest association with a woman's first child being taken into care at birth were mother being in care at the birth of her child (AOR = 11.10; 95% CI = 8.38-14.71), substance abuse (AOR = 8.94; 95% CI = 5.08-15.71), schizophrenia (AOR = 6.69; 95% CI = 3.89-11.52) developmental disability (AOR = 6.45; 95% CI = 2.69-14.29), and no prenatal care (AOR = 5.47; 95% CI = 3.56-8.41). Most characteristics of women deemed to be at high risk for having their child taken into care at birth are modifiable or could be mitigated with appropriate services.

We STILL need your help!

Continue informing us of your achievements and successes!

To enhance your webpage and Facebook page, we are looking for the following information and links – please let us know if and when you have the following information to share with us, our research community and practitioners!

- Links to pages of organisations in ID, social work, parenting, etc.
- Links to our Universities (Facebook pages and official websites)
- Links to Youtube videos (i.e. [We are Family](#)) and anything that would illustrate parenting with ID
- Pictures of families and parents with intellectual disabilities
- Any newly published or accepted articles
- Upcoming events-conferences
- Anything else you would like to 'advertise' on our sites

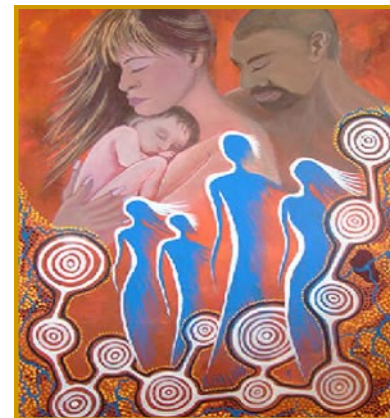


Image source:
www.aci.health.nsw.gov.au

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!***



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THANK YOU!

And thank you Amber for making this newsletter so beautiful!!

Your SIRG Executive: Margaret Spencer, Susan Collings, Traci Laliberte, David McConnell, Mikaela Starke, Hanna Sigurjonsdottir, Iva Strnadová and Marjorie Aunos

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